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ABSTRACT

This guidebook presents ideas about how families and case managers can use case management to increase the integration of people with developmental disabilities into their communities, and how public officials and advocates can promote the trend toward community integration. The guide advocates implementation of the integration philosophy, which holds that all people, regardless of the severity of their disabilities, belong in the community, and proposes that case management can translate this belief into practice. Chapter titles include: "'Mary Is a Person and My Sister': New Insights about People with Developmental Disabilities"; "Services for an Integrated Society"; "Case Management: A New Kind of Help"; "A Process for Building Community Connections"; "Monitoring, Evaluation and Advocating"; "The Case Management Team--A Partnership"; "Exploring New Roles"; "Using Regular Community Resources"; and "Achieving an Integrated Society." Appendices contain quality-of-life indicators, a regional service system plan, a statement in support of families, an options policy on quality of life, Minnesota case management appeal procedures, a 13-item bibliography on choice-making, an integration test for organizations serving people with developmental disabilities, and related materials. (JDD)

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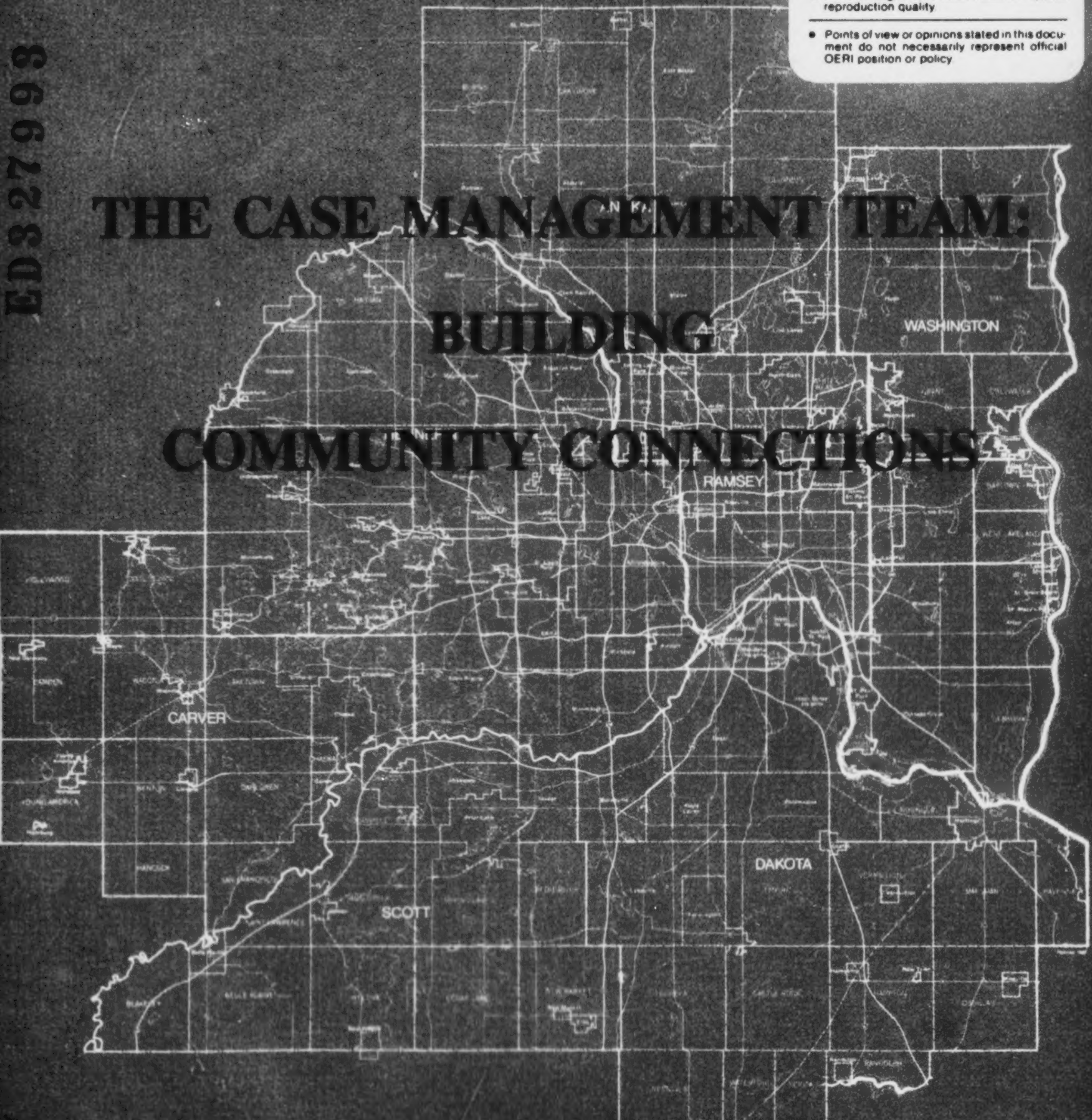
THE CASE MANAGEMENT TEAM:
BUILDING
COMMUNITY CONNECTIONS



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THE CASE MANAGEMENT TEAM: BUILDING COMMUNITY CONNECTIONS

1987

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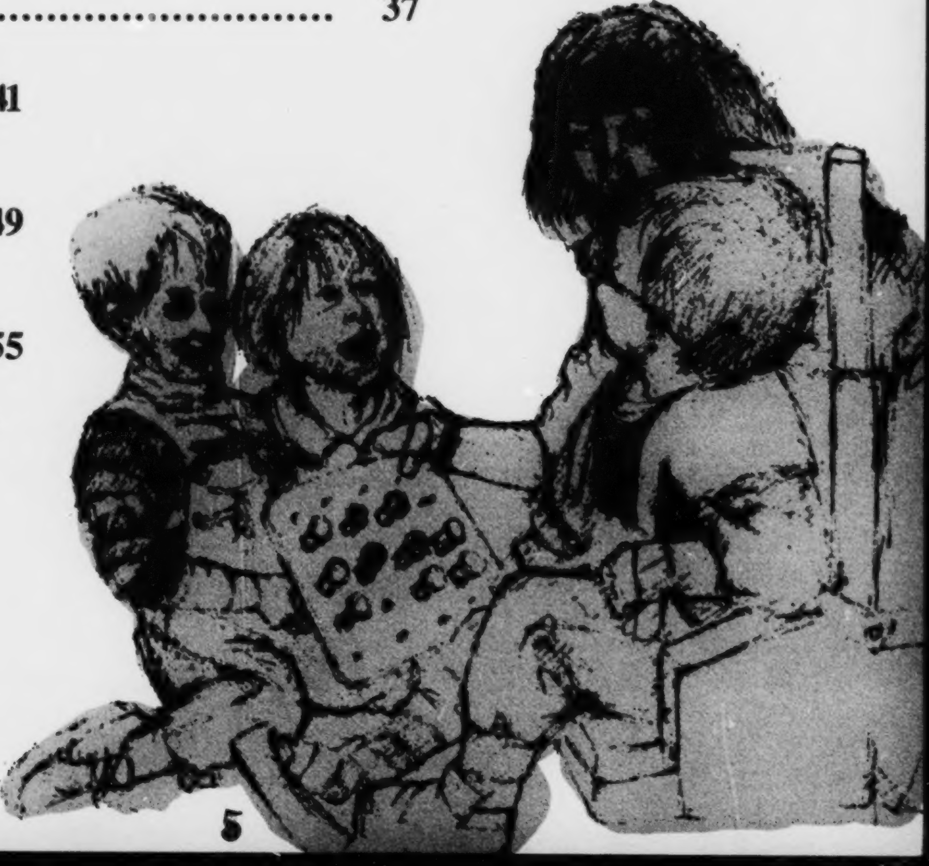

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Introduction

Today we have a clearer vision than in the recent past of how people with developmental disabilities can live in our society. New and more accurate information gained from nationwide research and demonstration projects makes this possible. *The Case Management Team: Building Community Connections* presents ideas about how families and case managers can use case management to increase the integration of people with developmental disabilities into their communities. Public officials, service providers and advocates may also find the booklet useful in understanding and promoting the trend toward community integration.

This publication will explain the ideas referred to here as the ***integration philosophy. The integration philosophy holds that all people, regardless of the severity of their disabilities, belong in the community.*** It assumes certain basic beliefs:

- Without any reservation, people with developmental disabilities are fully human.
- They are citizens whose human and civil rights are guaranteed by the Constitution and laws of the United States.
- They have the capacity to think and to learn even though their disabilities may seriously interfere with their developing and displaying these abilities.
- They can live successfully in an integrated society if they have appropriate support.
- Society has the obligation to help people with developmental disabilities to exercise their rights, to express their choices and to acquire the skills and behaviors they need to become participating and valued members of their communities.

This booklet proposes another assumption: ***case management can translate these beliefs into practice.***

The integration philosophy has influenced the development of very individualized and creative residential, educational, vocational and recreational services. However, public funding for such services is only beginning. Most public funding still favors the more traditional kind of services. For example, only a small proportion of vocational rehabilitation funds and Medicaid (Title XIX) funds are spent for the new services that do not require use of special facilities.

Strong advocacy by parents and professionals made it possible to begin funding the more integrative services. Continued demand can substantially increase the proportion of funding that is available. That is why parents and case managers should know more about the integration philosopy, its principles and practices.

The term "people with developmental disabilities" is used here to refer to people with severe, chronic mental or physical handicaps that become evident before age 22, that substantially interfere with their development in areas such as self-care, learning, communication and mobility, and that require ongoing, intensive services. They are people with handicaps such as severe and profound mental retardation, or with significant physical, sensory-motor, neurological or behavioral conditions. They frequently have combinations of these disabilities. The information in this booklet is intended to refer to this population rather than to people with more moderate handicaps, except where otherwise stated.

The term "family" is used throughout to mean parents, siblings, other relatives or legal guardians. For people with severe, multiple handicaps, the family is often an essential part of the decision-making process in case management. Although the individual is the primary focus of case management services, often families need help in maintaining a lifelong, beneficial relationship to the family member with developmental disabilities. This assistance should support, not replace, the family.

"Case manager" refers to county social workers who have been assigned case management responsibilities for people with developmental disabilities. They play an important role in helping their clients—people with developmental disabilities and their families—obtain services that are individualized and connect them to their communities. As leaders of the case management team, they need extensive knowledge about services and in-depth information about their clients.

The Case Management Team: Building Community Connections is only an introduction to the ***integration philosophy,*** to the exciting new information about people with developmental disabilities and to case management's relationship to integrated services. The references, recommended resources and information in the Appendices provide additional help for readers.

Way to Go

We grow up in a competitive society
Surrounded with norms determining
How, when and why to develop
Personal skills and behavior in
Order to survive and succeed now
And in the future.

Our parents, family members and
Teachers take the time to teach us
The rules on how, when and why.

Most of us develop according to
The norm, staying on the right
Track laid out and well used in
Society.

Most of us have journeys in life
That are safe, stimulating and
Progressive.

Far more often than not, we keep
Looking straight ahead locking our
Thoughts and concerns on that which
Only affects ourselves.

In doing so, we make people with
Developmental disabilities become
Shadows of fate, placing them in
Directions that will not be in
Our way, simply because they are
Unable to develop exactly
According to our norm.

Rather than take the time now
To design and construct tracks
To promote their individual
Development in self-care, learning
Economic self-sufficiency, independent
Living skills, mobility, self-direction,
And receptive, expressive language, we
Continue to ignore their existence and
Determine the fate of their journey in life.

They must start with today's
Opportunity to
Develop the personal skills and
Behaviors essential to live in
Present and future environments
That mostly include non-handicapped
People.

They must learn early how to
Select and pursue goals, and steer
Their lives in a direction headed for
Success.

All they ask for are early beginnings
That will get them as close as possible
To the norms and patterns of society,
Ultimate functioning.

We must listen.

We must learn.

Chapter 1

"Mary is a Person and My Sister": New Insights About People With Developmental Disabilities

Even today, people with developmental disabilities often are identified with their handicap. They are seen as members of an unfortunate group, incapable of all but minimal human development. They are separated from their families and provided services in special facilities that limit their contact with other people in the community.

Today, such beliefs and practices are changing. As one family member expressed it, "Mary is a person and my sister. She happens to have mental retardation, but that is something that is a part of her. It does not sum her up." (1) Communities and services are changing too, as the new information about innovative programs spreads.

What are Developmental Disabilities?

"Developmental disorders" are conditions occurring early in childhood that impair mental or physical structures, growth and maturation, and function. Most often progress through the normal development stages of childhood is delayed or absent. Autism, cerebral palsy, epilepsy, mental retardation, sight/speech/hearing disorders, spina bifida, and childhood and adolescent psychoses are the most common of these disorders. (2)

In the early 1970s, the strong efforts of advocates—parents of people with developmental disabilities and professionals—brought about changes in the law. The federal law authorizing services and funding for people who are mentally retarded was amended to add people with other developmental disorders that required similar services. This federal law is known as The Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100-146).

Based on this law, a developmental ***disorder*** is not considered a developmental ***disability*** unless it is chronic, severe, begins before age 22, and limits major functions such as language, mobility, learning, caring for oneself and independent living. People with developmental disabilities may include children, adolescents and adults. They often have been labeled as trainable mentally retarded; or as having autism, cerebral palsy or epilepsy; or having severe sight, speech or hearing impairments or as severely emotionally disturbed. The terms "developmentally disabled" and "severely handicapped" are used interchangeably here.

A Change in Perception

Developmental disabilities usually interfere with the ability to take care of oneself, move about, learn, communicate, make choices and make friends. Historically, it was believed that people with developmental disabilities actually lacked these abilities. As a result, their services over-emphasized the person's limitations or deficiencies and ignored their need to learn even basic skills.

> *Historically, it was believed that people with developmental disabilities actually lacked these abilities. As a result, their services over-emphasized the person's limitations or deficiencies and ignored their need to learn even basic skills. Now research and observations are challenging this traditional belief.*

Now research and observations are challenging this traditional belief. Individuals with developmental disabilities do have capacities for many basic functions, but in most circumstances have not been able to develop them well. Some professionals have concluded that the lack of observable abilities in many cases may be due more to limitations in the person's living situation and training than to the limitations caused by the disabilities. (3)

Several factors have influenced this new view of people with developmental disabilities:

- recent government-supported research, which has produced more effective service techniques;
- the use of new technological devices and equipment which has improved their communication, mobility and learning ability;
- successful achievements of students with severe handicaps who received free public education in local schools and thus remained with their families in their own communities; and
- higher expectations for those students by their families, service professionals and advocates. (4)

Changing Lives

Some children and adults with severe multiple physical and mental handicaps now are living in "ordinary" houses, apartments and condominiums. They are no longer segregated in specialized or medical facilities. Other children remain with their families and attend their local schools with neighborhood children who are not handicapped. Some adults are employed in community businesses and industries, and earn wages along with their nonhandicapped co-workers. They enjoy recreation where others also spend leisure time.

Another basic human need is social acceptance, or a sense of belonging in a community. Roles that confer community status include being a member of a family, a neighbor, friend, student, job trainee or employee, or a community volunteer. These are valued roles and everyone has a need to be valued. Families and professionals should see that these personal and social needs are met.

A new perspective on people with developmental disabilities gives primary attention to their human qualities and to the needs that arise from human nature rather than from the handicaps.

Of course, people with developmental disabilities need assistance and supervision from their families or trained staff to engage in some of these activities. And usually the environment requires adaptations or modifications so that people with developmental disabilities can participate. Many examples of these changes exist today in several parts of Minnesota and in other states.

New levels of achievement have called into question the traditional views that identify people with their handicap, and exclude them from certain opportunities because they are "retarded." This has led to low expectations for the person so labeled.(5)

A new perspective on people with developmental disabilities gives primary attention to their human qualities and to the needs that arise from human nature rather than from the handicaps. One of the most basic human needs is the development of a personal identity. One's identity or self-image emerges first within the family and later within a circle of friends. As one develops independence by having some control over one's life, by exercising choice and making decisions, personal identity is strengthened.

Attention to such needs has positive effects, according to observations of workers in special education services. In the past 10 years, professionals have worked directly with students whose accomplishments surpassed the previous generation of persons with the same types of severe and multiple handicaps. These professionals have begun to identify some common factors in the lives of these students.

One of the most notable factors is that most of them lived at home with their families. They developed positive self-images that came from their families' acceptance of their individuality and their value as family members. Besides living at home and being a neighbor, their roles as students, job trainees or employees also gave them more opportunities to meet and talk with others and be accepted as regular members of their communities. Thus they achieved higher community status than other people with developmental disabilities who lived in segregated and insulated environments.

In addition to people living in their communities, having family ties and being part of the neighborhood, another striking difference about them has been observed. Their families and neighbors, their teachers, classmates and employers had higher expectations for them. These expectations reinforced their personal and community status and encouraged them to achieve more. To encourage higher goals for others with similar severe handicaps, professionals proposed new ideas and applied and tested them.

Their findings have generated several principles to guide the training and environments of individuals with developmental disabilities. Data from their research has been distributed through national and local publications, conferences and workshops. The philosophy that emerged from these collective activities is called here the ***integration philosophy. The integration philosophy proposes that all people with developmental disabilities belong in the community.*** It is considered by many to promote a better quality of life than traditional services.

As news of this philosophy has spread, attitudes and expectations for people with developmental disabilities have been reexamined. It also has required a rethinking about the kinds of services people with severe handicaps were receiving. More families and professionals began vigorously to challenge traditional ideas about people with severe handicaps and what constituted appropriate services.

> *The integration philosophy proposes that all people with developmental disabilities belong in the community.*

The 1984 amendments to the Developmental Disabilities Act stated that the purpose of the law was to "increase and support the ***independence, productivity*** and ***integration into the community*** of persons with developmental disabilities." But people with severe handicaps had not been measured in these terms. Nor did their services produce significant progress in these areas. Therefore a new concept of services was needed. To secure these results, services should be redefined as ***whatever arrangements (personal assistance and environmental adaptations) are needed by individuals to become more independent, productive and integrated in their communities.***

Thus, arrangements or services must no longer be insulated or segregated in specialized facilities. People with developmental disabilities must be better connected to their communities. They must be provided the individualized support they need to live satisfying lives in an integrated society.

NOTES

1. Theresa J. Lippert. "President's Perspective." *Parentalk.* 37, No. 9, 1987. Association for Retarded Citizens, St. Paul, MN.
2. Metropolitan Council. "What Is a Developmental Disability?" Unpublished staff report. St. Paul, MN 1981.
3. "Conceptual Basis for Community Services." Washington Department of Social and Health Services, Division of Developmental Disabilities. Olympia, WA. 1982.
4. Metropolitan Council. "Developmental Disabilities Regional Policy Plan of the Metropolitan Council." St. Paul, MN. 1985.
5. James F. Gardner and Michael S. Chapman. *Staff Development in Mental Retardation Services.* Baltimore: Paul H. Brookes. 1985.

OTHER RESOURCES

1. *A New Way of Thinking.* 1987. Free booklet available from the Minnesota Governor's Planning Council on Developmental Disabilities; State Planning Agency, 300 Centennial Office Building, 658 Cedar St., St. Paul, MN 55155. Explains the integration philosophy simply and briefly. Gives real-life examples of how it is working in Minnesota and other states.
2. "Richard and Donna: A Little Bit of Faith." Videotape on supported employment available on loan from the Minnesota Supported Employment Project, Division of Rehabilitation Services, 5th Floor—390 Robert St., St. Paul, MN 55101. 612 296-5629 or 1-800-328-9095.
3. *Community Integration for People with Severe Disabilities.* ed. Steven J. Taylor, Douglas Bicklen and James Knoll, 1987. Available from Teachers College Press, Teachers College, Columbia University, 1234 Amsterdam Ave., New York, NY 10027. Also available from lending library of the State Developmental Disabilities Program Office, 300 Centennial Office Building, 658 Cedar St., St. Paul, MN 55155. 612 296-4018 or 612 296-9962 TDD. More than 20 professionals examine the major issues in community integration and what arrangements foster the greatest degree of integration. Chapters are easy to understand and useful to families as well as professionals.

Kristina

She has mental retardation, and
Is nine years old.

Ultimate functioning for Kristina
Is learning how to count,
Using real-life experiences
Rather than be taught
How to count blocks.

Ultimate functioning for Kristina
Also is learning how to write her
Name by practicing how to draw
Lines between dots mapped out
For the letters K,r,i,s,t,i,n,a
Rather than be taught the
More difficult way of drawing
Letters.

She's proud to be able to
Count and measure food and
Water for her dog and cat.

She was thrilled to give her dad
A valentine signed "Love, Kristina."

Way to go, Kristina.

Congratulations to her parents and
Teacher.

Chapter 2

Services for an Integrated Society

Families, case managers and other service providers are accepting these new insights about people with developmental disabilities and want to help them build community connections. To accomplish this, families and professionals also need to understand:

- how and why changes in services occur, and
- what services for an integrated society are like.

Social services developed as people recognized that some children have conditions that require great amounts of help to ensure their growth and development. The United States acknowledged these conditions by enacting public policies and laws. To ensure that people with severe handicaps will be able to exercise their human and civil rights several federal laws were passed. The laws generally stated that people with substantial mental or physical disabilities that begin early in life need significant, continuing help to meet their needs for housing, education, employment and income. The most important federal laws include:

- The Mental Retardation Facilities and Community Mental Health Centers Construction Act, 1963
- Social Security Amendments for Intermediate Care Facilities for the Mentally Retarded, 1965 and 1971
- Title XVI of the Social Security Act, 1972
- Vocational Rehabilitation Act Amendments, 1965 and 1973
- Education of All Handicapped Children Act, 1975

Health care and day programs became available through other amendments to the Social Security Act in 1965. One of the more significant laws, the Developmental Disabilities Act, 1970, and all later amendments specifically singled out persons with severe, chronic handicaps. The act includes a bill of rights for persons with developmental disabilities, identifies nationwide priority needs and creates a council in each state to advise the governor on those needs. Although many states already had laws to protect and aid people with handicaps, the federal laws gave states more specific responsibilities for people with severe handicaps and provided additional money to carry out those directions.

Looking at earlier federal and state laws shows that the first services they established were based on early beliefs about developmental disabilities. For example, at one time, people with mental retardation were considered sick, subhuman, objects of pity or fear, or eternal children.(1) So the early services reflected those beliefs. Shifts in views over the last 100 years produced three distinct types of service systems. The systems can be described as ***segregated, insulated*** and ***integrated.***

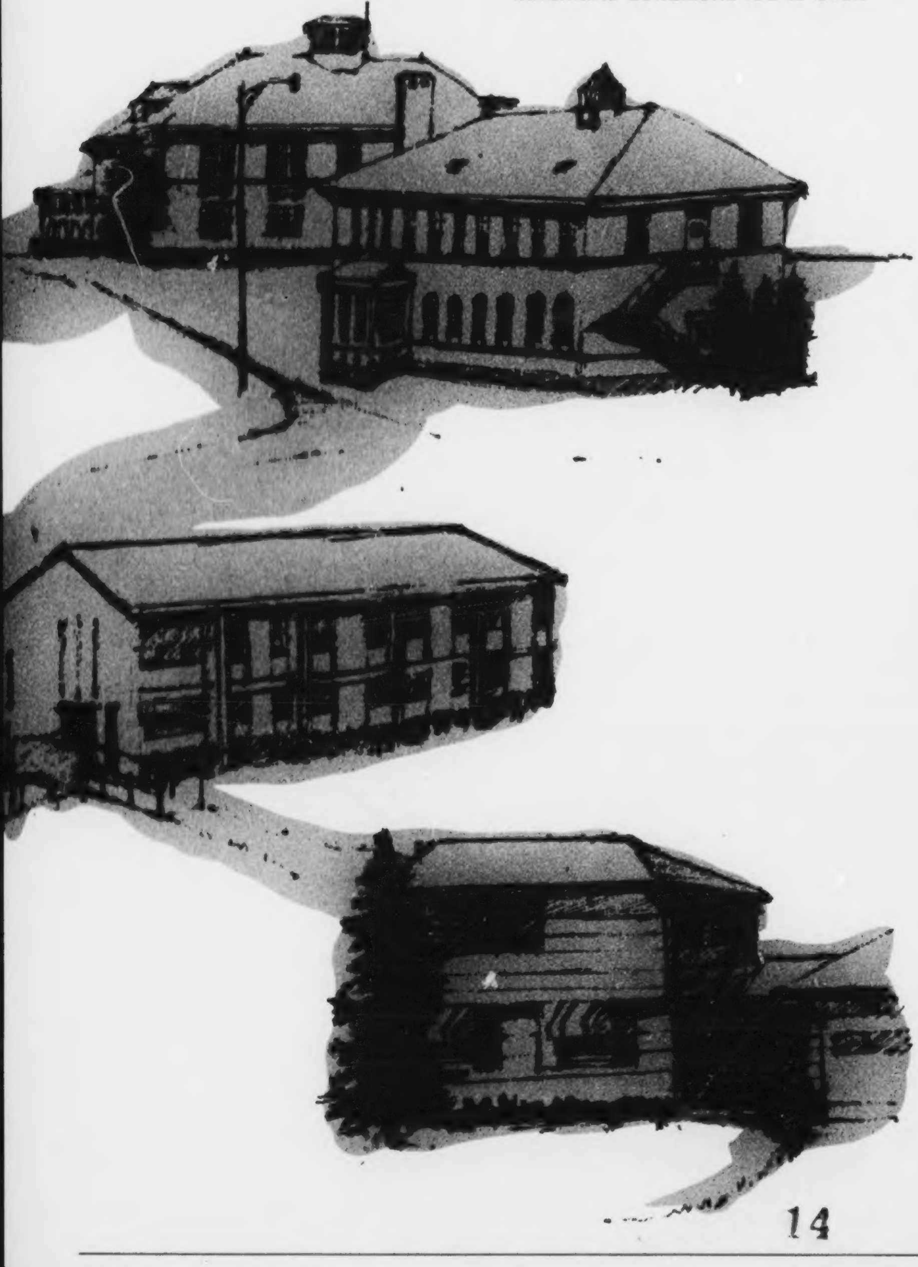
Developmental Disabilities Service System

Type	Attitudes	Expectations	Services
Segregated	Negative; devalued; objects of fear, pity, charity	None, low	Large institutions; isolated; custodial care
Insulated	Limited potential; identify person and performance with disability; can learn only in separate, specialized locations	Moderate for people with higher IQ scores; still very low for individuals with severe handicaps	Disability-focused; sheltered; specialized; facility-dependent services (ICFs-MR, DACs and sheltered workshops); community presence
Integrated	Positive; valued person; unknown potential	High; capacity limited mostly by training and environments	Individualized arrangements; personal assistance and environmental modifications to supplement person's strengths

Segregated Services

Segregated services were based on the belief that people who acted and looked different were a danger to the public. In the 1890s and early 1900s, this idea led to many people with mental retardation or severe epilepsy being isolated. They were sent from their homes and communities to institutions far away in unpopulated areas. They were given basic necessities—food, shelter, clothing and minimal health care. They lived in institutional buildings.

Mental retardation was often confused with insanity or was thought to be a condition that could not be improved, so no training was provided to teach needed skills. As more and more people were sent away from their homes to institutions, institutionalized systems in all states grew. Overcrowding and increasingly inhumane conditions led to even more deterioration in the health and behavior of the people who lived there. The way institutions were operated reflected society's belief that the residents were subhuman, with no ability to learn.



Insulated Services

In the 1960s, the emphasis on civil rights influenced ideas about people with mental retardation, epilepsy and other developmental disabilities. It also became more apparent, by that time, that some people with these disabilities in a milder form could benefit from training and education. About this time a new concept, "Normalization," originating in the Scandinavian countries, was introduced in the United States. Wolfensberger's book, The Principle of Normalization in Human Services,(2) became an accepted standard in this country.

Simply stated, the normalization philosophy holds that people with severe handicaps can grow and develop if provided with resources and assistance like that available to other people in society. Normalization created a more hopeful vision of people with developmental disabilities—of outcomes they could expect and of the means to achieve them.

At about the same time as the normalization philosophy spread throughout this country, parents of people with mental retardation began to organize. The Association for Retarded Citizens began in Minnesota and expanded into many other states. The parent advocacy movement launched an intensive educational effort to inform federal, state and county legislators about the deplorable conditions in the public institutions. Parent advocacy has been a critical factor in passing both federal and state legislation.

In the 1970s legal action accompanied the spread of the normalization philosophy and the strong parent advocacy movement. Several major class-action suits against institutions and administrators brought about rulings on the rights of persons with mental retardation who were in state institutions.[3] Foremost among these rights was the right to treatment in the least restrictive setting. It became one of the principles of the integration philosophy.

The belief and values expressed in the normalization philosophy, the parent advocacy movement and court actions changed federal policy and legislation. States and county governments were required to establish the needed services in local communities. People began to leave institutions and return to their own communities. Some new community-based services had already begun in the late 1960s and early 1970s in Minnesota. But even then it was believed that people with severe handicaps could only grow and develop from training in specialized facilities.

During the 1970s daytime training centers, sheltered workshops and residential facilities expanded throughout the state. Although these facilities were located within communities, the people using them remained insulated from others. They were offered little or no daily contact with nonhandicapped people other than their own families or program staff. People with mild or moderate mental retardation eventually developed relationships with others, but people with severe or profound retardation or other severe disabilities were still sheltered or insulated from the general population.

Often their extreme dependence on others—because of physical or sensory impairments, lack of communication skills, or serious behavioral problems—were thought to make them more vulnerable to risk, ridicule or abuse by other members of the community. They were thus insulated as they received services in special facilities to meet their "special needs."

In 1975, a federal law was passed giving all children with handicaps, including those with developmental disabilities, the right to free, appropriate education in the least restrictive environment. Two important things happened because of this law. First, most families were able to keep their children at home. Even children with the most severe handicaps developed skills and behaviors previously assumed impossible. Parents and educators saw that remaining at home and receiving formal teaching resulted in the higher achievements of students.

Second, families of these students began to seek future services that would allow their children to continue their roles as citizens in their own community. For example, after school years, adults typically seek employment. Thus, more parents and professionals began to reject traditional post-school services in special facilities such as "sheltered workshops." They began to demand training for real jobs in business and industry rather than simulated work in insulated or sheltered settings. They began to expect more of and for their children.

> *Some feel the normalization philosophy is too general. A strong clear statement of the new vision of people with developmental disabilities is needed. The integration philosophy fills that need.*

Integrated Services

More professionals and parents of older, noneducated adults began to hear about some of these successful programs—newer types of living arrangements, supported employment and integrated recreational programs using community settings and resources. They began to demand and create the newer kinds of services all across the country.

The service system began to change once more: from segregated and insulated to integrated. Integrated services offer the following characteristics:

- They are individualized.
- They focus on developing skills and behaviors needed for daily living functions.
- They are appropriate to the age of the individual.
- They are provided in natural rather than insulated or artificial settings.
- They offer continual opportunities for making choices and reducing dependence.
- They promote wider association with nonhandicapped people, beyond the person's family and paid staff.

Some feel the normalization philosophy is too general. A strong clear statement of the new vision of people with developmental disabilities is needed. The integration philosophy fills that need. It proposes that people with developmental disabilities can and should participate in the life of their communities and that communities should be open inclusive and support their integration.

This philosophy has produced a number of specific principles or guidelines. Some have been stated by professionals in special education. Some reflect guidelines developed by other service professionals and parents. These principles can be used as standards for case management, residential, vocational, educational, health, recreational and all other services.

Integration Principles

- ***Individualization.*** The selection or development of a specific package of services should be based on an individual's human needs as well as on the person's unique combination of abilities and limitations.
- ***Ultimate Criterion.*** Skills and behaviors to be taught should relate directly to functions an adult will need to live a satisfying life in an integrated society.

- ***Least Restrictive.*** Services, by the manner in which they are provided or where they are offered, should not unduly limit or restrict the personal rights and preferences of individuals.
- ***Natural Support.*** Families provide the most natural support. They should be assisted when necessary to maintain their children who are developmentally disabled, as long as they are able and willing to do so and as long as it benefits the child. Adults should be helped to maintain family ties and to develop friendships. Assistance for individuals and their families should be sought from other natural support networks that include relatives, friends, neighbors, religious groups, civic organizations, places of employment and social clubs. If these natural networks cannot maintain the needed supports, even with special adaptations, then more formal, specialized arrangements should be made.
- ***Partial Participation.*** Activities and environments should be modified, and assistance given, so that people with developmental disabilities can participate, even in part, in the same activities and resources offered to others.
- ***Natural Proportion.*** Services should integrate people who are severely handicapped with nonhandicapped people in the approximate proportion each has to the whole population.
- ***Self-Determination.*** Services should increase the ability and the power of individuals to exercise personal choice and to increase control of their own lives.

Services incorporating these principles, such as integrated education and recreation, supported employment and supported living arrangements, have proven very effective. They have increased individuals' physical, personal, social and community status. If these principles are missing, the rights of people who are severely disabled are more restricted than those of people without handicaps.

In addition to learning and using the principles above, families, case managers and others may be interested in other criteria and guidelines that integration practitioners have proposed. Two examples are found in Appendix A and B: "Seven Quality of Life Indicators," 1987, and "Developmental Disabilities Regional Policy Plan," 1985.

NOTES

1. Wolf Wolfensberger. *The Principle of Normalization in Human Services.* Toronto: National Institute on Mental Retardation. 1972.
2. Ibid.
3. Major class action suits: Wyatt v. Stickney in Alabama, 1972; Welsch v. Likins in Minnesota, 1974; United States v. Solomon in Maryland, 1974; New York Association for Retarded Citizens v. Carey (Willowbrook), 1975; and Pennsylvania Association for Retarded Citizens v. Pennhurst, 1977.

OTHER RESOURCES

1. "Why Integration?" 1987. Luanna H. Meyer. Available from University of Minnesota Consortium Institute for the Education of Severely Handicapped Learners. 6 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455; 612 624-6300. Cost: $1. Questions the "separate but equal" concept of services and discusses why integrated services are preferable because of cost-effectiveness, in order to build community supports and to provide a better quality of life.

   The Consortium Institute will also send a free list of similar resources on other contemporary ideas and strategies for integration, communication intervention, excess behavior, parent-family issues, program evaluation and assessment and therapeutic recreation/leisure.

2. "Test Your School's IQ: Integration Quotient" and "Test Your Program's IQ: Integration Quotient." 1987. Free brochures available from the Minnesota Governor's Planning Council on Developmental Disabilities, State Planning Agency, 300 Centennial Office Building, 658 Cedar St., St. Paul, MN 55155; 612 296-4018 or 612 296-9962 TDD. Checklists of questions for families and staff to assess integration efforts of local school districts and other agencies and organizations that provide services to people with developmental disabilities.
3. Project Dakota Early Intervention: Tailor Made." 1986. Linda Kjerland. Free brochure available from Project Dakota Outreach; 680 O'Neill Dr., Eagan, MN 55121; 612 455-2335. Describes successful program for providing toddlers with integrated early intervention activities.
4. "Developmental Disabilities Regional Plan of the Metropolitan Council." 1985. Free publication available from the Metropolitan Council, Data Center, 300 Metro Square Building, 7th and Robert Sts., St. Paul, MN 55101; 612 291-6464. Traces the new trends in services and lists goals, guidelines and criteria for an integrated service system.

ANOKA
WASHINGTON
HENNEPIN
RAMSEY
CARVER
SCOTT
DAKOTA

17

Shane

He has a serious form of Spina Bifida.

At birth, his spinal cord
Resembled the flat shape of a
Rubber band, whereas his
Parents' resembled the circular
Width of one's finger.

Ultimate functioning for Shane
Was learning how to use a
Caster cart, resembling a
Mechanic's creeper or raft,
Equipped with a backrest, two
Wheels at the end, a front
Wheel, and ample space
Surrounding his legs.

It is Shane's way to get
Around the house, play
Outside with friends, and
Haul his toys. With his
Arms positioned over each
Side, and hands placed
On the floor,
Shane is able to push wherever
His caster cart can go.

At fifteen months, the cart
And dash stage of development
For most non-handicapped toddlers,
Shane was able to dart with his
Cart and dash with a lash securing
His body.

At four years old, when most kids
Are Saturday morning cartoon fans,
Shane was able to turn channels
With a clothespin his parents
Attached to the dial, a
Challenge overcome through
Creativity.

Several special education administrators
Opposed Shane's enrollment in a
Neighborhood school, claiming he would
Do better academically in a special
Learning environment.

His parents wanted their son to
Learn socialization behaviors through
One-on-one contact with non-handicapped
Students, rather than be taught how
To do so through special-education
Teachers and books.

Shane's above-average academic
Performance dropped slightly at
The neighborhood school, whereas his
Ability to socialize has scored sky
High.

A promising mixture of personal skills
And behaviors to function in present
And future environments which include
Mostly non-handicapped people.
Third-grade teachers predict
Shane will either serve as our nation's
President or become a sales executive
For a major firm.

Figuratively speaking, he has his feet
Well positioned on the ground, running
In the right direction.

Way to go, Shane.

Congratulations to his parents.

Chapter 3

Case Management: A New Kind Of Help

Before integrated services were conceived, social workers helped families and their children who were severely handicapped primarily through direct counseling. Until the early 1970s the usual referral for service was to a public or private institution. Once a person was placed, the institution took care of all custodial needs, and the county social worker's role was minimal compared with today.

When the move to community-based services began, a variety of separate services was established, such as residential, day activity, transportation, health, educational and vocational. They were provided in specialized facilities located in different areas of cities or counties. Each service was supplied by a different agency or organization. Some were public, others private. Each service had different eligibility rules, based on serving people with a particular disability or on the source of funding. Not all services were available to those who needed them. In addition, people with severe handicaps usually needed several different services at one time.

For these reasons, finding and obtaining services became extremely complicated. Families needed additional kinds of assistance. They needed professional help to assess their children's needs and determine their eligibility for certain services. They needed help to determine what services were available, and to obtain them.

In addition, since most services were paid for with public funds, the counties that authorized the services also were supposed to monitor and evaluate them to see whether clients were provided what was promised. And, when there were no services, or eligibility was denied, someone had to help families meet their needs in other ways. These additional professional duties also required new reporting responsibilities.

The county social workers, who were the traditional professionals with responsibility to help individuals with developmental disabilities and their families, now had to add these new functions to their direct counseling and referral duties. These new functions were called *case management.*

Families needed additional kinds of assistance. They needed professional help to assess their children's needs and determine their eligibility for certain services. They needed help to determine what services were available, and to obtain them.

Minnesota laws and regulations describe the state's case management system. The law gives responsibility for case management to the Minnesota Department of Human Services (DHS). This state agency has delegated direct provision of case management services to the counties for several reasons. Counties use local funds to pay for these services and other support services they purchase for people with developmental disabilities. Counties also know better what local resources or support services are available for their residents.

Special state regulations, called Rule 185,(1) give the specific standards and responsibilities counties must observe in providing case management services. Rule 185 states who is eligible for case management services, what services are to be provided, who are the participants in case management, and what forms should be produced.

Who Is Eligible

To receive case management services, a person or the family ***must request case management services*** from the county that has financial responsibility for the person.

People who are or may be mentally retarded or have a related condition are eligible. That means a person must have a diagnosis of mental retardation with an I.Q. score of 70 or below and lack independent living skills, or have a diagnosis of a related condition. "A related condition" means a severe, chronic disability that occurred before age 22, and impairs general intellectual functioning, or interferes with self care, mobility, communication, self-preservation and community integration, or requires service or treatment similar to what is required by people with mental retardation.(2) A call to the local county social services (or human services) department will provide more specific information about which county has financial responsibility and makes the determination of eligibility.

Services To Be Provided

The kind and number of case management services provided depend on which laws or regulations authorize them. A definition of case management services exists in federal law, in the Developmental Disabilities Act (P.L. 100-146):

> The term "case management services" means such services to persons with developmental disabilities as will assist them in gaining access to needed social, medical, educational, and other services. It calls for continuing follow-up of the changing individual and family needs. The relationship between a case manager and the family may be life-long. The case manager leads the team, provides information, coordinates needed services and monitors the individual's progress.

States also have laws and regulations authorizing case management. In Minnesota's Rule 185, case management is defined as:

> "Identifying the need for, planning, seeking out, acquiring, authorizing and coordinating services to persons with mental retardation or related conditions."[3]

Participants in Case Management

Rule 185 includes eligible people with developmental disabilities and their families as participants with the case manager as the major decision-makers in determining goals, objectives and services for the person. The case manager is usually a social worker employed by the county. In a few counties, case management services are purchased by the counties from other agencies. If the person with developmental disabilities is under state guardianship, a social worker other than the person's case manager acts as the person's legal representative.

Parents or another legal representative are included when the person with developmental disabilities is a minor or an adult who has been judged by the court to be unable to make informed decisions. For other

individuals with severe handicaps, families or an advocate may participate in discussions, but not in final decisions. Regional service specialists, qualified mental retardation professionals and other professionals and service providers frequently join in the discussions when they have additional information that is needed for decision-making.

The involvement of the person and family began in 1972 when the Department of Human Services established a policy that allowed parents or legal guardians to become involved in planning and decision-making for their children or wards who were mentally retarded.[4] Federal policies and laws also recognize that parents have unique insights about their children, that parents could gain knowledge and become better advocates through involvement in decision-making, and that their children could benefit when parents and professionals work together.[5] (See Appendix C for a statement on family support.)

> ***"To say for our children what they would say if they had access to power, that is our responsibility as parents. We have obligations to repair and strengthen the bridges Congress has built to bring disabled Americans into the mainstream of life."***
>
> *Senator Lowell Weicker (R.CT)*

> *Rule 185 includes eligible people with developmental disabilities and their families as participants with the case manager as the major decision-makers in determining goals, objectives and services for the person.*

Case Management Results

Case management results in several written records: individual assessment, screening, Individual Service Plans and Individual Habilitation Plans. These are explained below.

Individual Assessment: Once a person becomes eligible for case management services, the county is responsible to develop an individualized assessment of the person. Rule 185 states that the assessment should include information about the person's current health and physical development, intellectual functioning and adaptive behavior, social skills, self-care skills, communication skills, community living skills, vocational skills, current physical and social environments, and legal status (need for a legal guardian).

The rule also says that "the assessment must result in specific service recommendations," such as the Individual Service Plan (ISP). The needs identified in the ISP are the basis for authorizing services. Therefore assessment should be comprehensive, accurate and individualized. Yet Rule 185 says little or nothing about assessment addressing the person's basic human needs for a real home, learning opportunities, a job in a community business, developing friendships and enjoying leisure time.

Screening: Whenever a person's assessment indicates the need for 24-hour supervision and assistance, such as provided by an Intermediate Care Facility-Mental Retardation (ICF-MR), the person must have a screening. The screening is the specific determination of whether or not this level of care is needed or will be needed within one year. It also identifies other services that could prevent or delay the use of the more restrictive ICF-MR level of care as well as the source of funding for alternative services. These alternative services are called "home and community-based services" and require a waiver (special permission) to obtain them.

The Individual Service Plan (ISP): This is a written plan prepared by the case manager that includes:

- a summary of the diagnoses, assessment and screening information,
- the person's goals and objectives,
- ***all*** the services needed by the person, and, in some cases, services needed by the family to achieve the goals and objectives (including the type, number and frequency of services),
- the actions and timetable to obtain the services, including needed services not currently available,
- information to be reported by service providers, and how often, and
- the signature of the person with developmental disabilities and/or the family (or legal representative).

Minnesota statutes and regulations specify that, whenever possible, the list of services selected should indicate the services preferred by the individual and/or the family, and must reflect the least restrictive environment that promotes the maximum independence of the person.[6] This is consistent with the integration philosophy.

The Individual Habilitation Plan (IHP): This written plan is also prepared by the case manager in consultation with those providing the services listed in the ISP. Its pur-

> ***"The least restrictive environment . . . allows persons with disabilities to participate to the maximum extent possible in everyday life and to have control over the decisions that affect them. It is an environment that provides needed supports in such a way that they do not interfere with personal liberty . . . with a person's access to the normal events in life."***
>
> *—"News Digest," National Information Center for Handicapped Children and Youth*

pose is to ensure coordination among all the services being provided and consistency with the goals or outcomes specified in the Individual Service Plan. The IHP should include for ***each*** service:

- short-term objectives to achieve the long-range goals and (annual) objectives of the ISP,
- how providers will offer services,
- who the provider designates as responsible for the service,
- measurable behavior criteria to determine effects of services,
- timetable for and frequency of providing services,
- special resources needed to carry out the IHP,
- frequency of provider reports on the person's progress,
- frequency of case manager's monitoring of services,
- signature of the person with developmental disabilities and the family documenting agreement with the IHP's consistency with the ISP.

How the Integration Philosophy Affects Case Management

Minnesota's Rule 185 specifies what case management services are to be provided and minimum standards for how to provide them. The rule gives little indication of how to use case management services to obtain direct services that promote measurable changes in independence, productivity and community integration.

Because of the new insights about people with severe handicaps, the people involved in case management—the case managment team—need to consider more creative approaches to the traditional case management process prescribed by Rule 185.

NOTES

1. Minnesota Statute, Sec. 9525.0015 to 9525.0165.
2. Minnesota Statute, Sec. 9525.0180-.0195. "Related conditions" exclude mental illness, chemical dependency, senility, muscular dystrophy and multiple sclerosis.
3. Minnesota Statute, Sec. 9525.0015, subd. 4.
4. Minnesota Department of Public Welfare. "Rights and Responsibilities of Parents, Retarded Family Members and Facility Personnel in Program Planning in Private and Public Residential Facilities" *Retardation Services Division Program Plan*. St. Paul, MN. 1972.
5. M. Gerry. "Procedural Safeguards Insuring That Handicapped Children Receive Free Appropriate Public Education." *News Digest*. No. 7. 1987. National Information Center for Handicapped Children and Youth. Washington, D.C.
6. Minnesota Department of Human Services. Division of Developmental Disabilities. Rule 185 Discussion Papers: Series 1, Number 3, "Individual Service Plan." St. Paul, MN. 1986.

OTHER RESOURCES

1. Rule 185: Minnesota regulations governing case management standards and county responsibilities. Available free from the Minnesota Department of Human Services, Division of Developmental Disabilities, Space Center, 444 Lafayette Rd., St. Paul, MN 55155; 612 296-2160.
2. County case management services information series available from PACER 4826 Chicago Ave., Minneapolis, MN 55417 612 827-2966, V/TDD.

ANOKA
WASHINGTON
HENNEPIN
RAMSEY
CARVER
SCOTT
DAKOTA

Sarah

She has a hearing and speech
Impairment. At the age of
Thirteen months, a critical
Infection silenced her ears to
The sounds we hear, express, learn
Through, and function by.

Partial Participation for Sarah
Is sign language, picture cards,
Role playing, blinking light
Fixtures, and a dog trained to
Notify her of significant sounds.

Through sign language, Sarah will
Learn how to communicate in the
World of sound, using her hands
To speak.

Her parents felt lost for words
To describe their joy the first
Time Sarah learned to say, "Hi,
Mom and dad."

Picture cards will teach Sarah the
Visual image and definition of words,
Helping her work through the
Complexity of those spelled the same,
But with different meanings.

She'll learn that the word, bow,
Defines the ribbon in her hair,
The equipment her dad uses to hunt
Deer, and the courtesy movement
Her brother makes following his
Piano performances.

Role playing will help Sarah
Learn and apply words associated
With specific functions, teaching
Her communication skills for
Roles she will assume as a child,
Teenager, and an adult.

Blinking light fixtures located
Throughout her home will encourage
Sarah to seek independence with
Confidence, spending the time doing
What she'd like in rooms by
Herself.

They give her and her parents security
In knowing a light will blink
Whenever attention is desired.

A dog, trained to notify Sarah of
Significant sounds, will promote
Self-care by giving her an opportunity
To handle responsibilities that require
Hearing.

Her pet keeps an ear open for a fire
Alarm, a weather warning, someone
Knocking at the door, and the presence of a
Person walking behind Sarah.

Sarah just celebrated her sixth birthday.

She's always on the go to learn words;
She always has something to say. She's
Eager for role playing, she enjoys
Drawing picture cards with her parents.
She has her operation of the blinking
Light fixtures down pat, and she walks
Around the block in pride with her dog.

Through adaptations, Sarah can
Hear and express the sounds of life
With a stronger appreciation than some
Persons who can listen and talk with
Little effort.

Way to go, Sarah.

Congratulations to her parents.

Chapter 4

A Process For Building Community Connections

Among the elements needed for effective case management is ***a well-defined process.***(1) This means that the individual and the family receiving case management should have a good understanding of what case management is and how it operates.

Minnesota's Rule 185 establishes standards of case management for counties. Yet few case management clients know of its existence. There are few, if any, other written materials that give clear, adequate information about the process for all the people involved. Since Minnesota orders the active participation of the person with developmental disabilities and the family (unless the person is his or her own legal guardian), they need this basic information. As new case managers and service providers enter the system, and as concepts of services change from facility-dependent models to less formal arrangements, these people also need to learn more about the case management process than Rule 185 contains.

Professional literature on case management generally describes the process in terms of five major functions: assessing, planning, monitoring, evaluating and advocating. Since these functions correspond to the major case management responsibilities in Minnesota's laws and regulations, these terms will be defined in the rest of this chapter and Chapter 5, in discussing use of an integration approach.

Assessment

Assessment is the continuous gathering and interpreting of comprehensive and accurate information about a person.

This usually includes medical, health, psychological, residential, educational, vocational and family-history information. It may be obtained through interviews or direct observation. Rule 185 requires a professional diagnosis on the cause or nature of a person's disabilities and usually a numerical score measuring an adult's mental and physical abilities on some standardized scale.

Although this information traditionally focuses on the person's deficiencies, it has been needed to establish eligibility for certain services. However, the newer philosophy suggests that eligibility for services should be determined by a person's human and functional needs rather than I.Q., other numerical scores or precise type of disability. Changes in federal law are needed to address this problem.

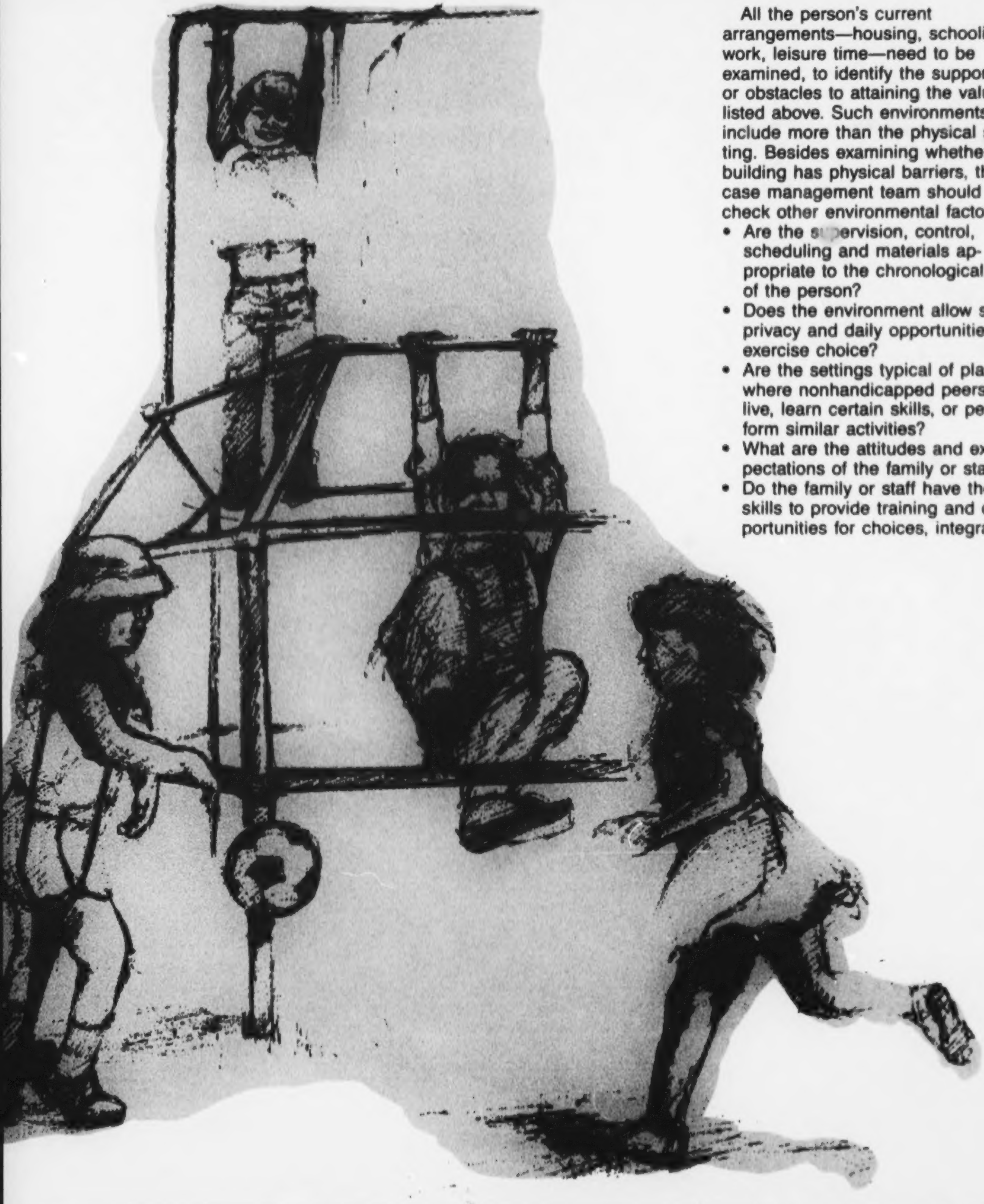
Successful "supported employment" in Minnesota and other states has demonstrated that a person's past failures cannot predict future job performance. This suggests that case management assessment should have a focus broader than the person's disabilities. The integration philosophy requires primary focus on the person as a human being and a member of the community.

As a human being, the individual has a need for the same things all people value: a family, a home, financial means, some control over one's life, a positive self-image, well-being, social acceptance, a sense of accomplishment and friends. Determining what the person has or is missing in regard to each of these values is what should be considered in assessment.

As a human being, the individual has a need for the same things all people value: a family, a home, financial means, some control over one's life, a positive self-image, well-being, social acceptance, a sense of accomplishment and friends. Determining what the person has or is missing in regard to each of these values is what should be considered in assessment.

To begin this new kind of assessment, it helps to think of the person in many of the relationships typical for someone the same age: son/daughter, brother/sister, tenant/owner, roommate, student, coworker, friend and relative. Other roles come to mind as functions are considered: cook, cleaner, table-setter at home; a customer shopping for clothes, groceries and recreation equipment; member of a religious congregation or other organizations; user of a library, community center, playground.

Other areas to consider in assessment are what a person likes to do and is able to do independently or with help. This kind of assessment provides clues to what motivates and interests the individual. It emphasizes abilities and seeks unknown capacities.



All the person's current arrangements—housing, schooling, work, leisure time—need to be examined, to identify the supports or obstacles to attaining the values listed above. Such environments include more than the physical setting. Besides examining whether a building has physical barriers, the case management team should check other environmental factors:

- Are the supervision, control, scheduling and materials appropriate to the chronological age of the person?
- Does the environment allow some privacy and daily opportunities to exercise choice?
- Are the settings typical of places where nonhandicapped peers live, learn certain skills, or perform similar activities?
- What are the attitudes and expectations of the family or staff?
- Do the family or staff have the skills to provide training and opportunities for choices, integration

and varied experiences in the community?

The case management team needs to observe the person to appropriately assess all the environments. To judge the attitudes and skills of those who work with the person, the team needs to ask:

- Do they encourage less dependence on family and staff?
- Do their attitudes and skills or time schedules promote friendships with people who are not handicapped?
- Are all the person's needs provided by "developmental disabilities organizations" or have attempts been made to find community resources used by people who are not handicapped?
- If these community resources are not adequate, have any modifications or adaptations been tried?

Naturally, information about the person's disabilities is part of the assessment. However, the disabilities should be considered in terms of the extent to which they prevent the person from functioning in integrated settings. Do current services include personal assistance or environmental adaptations to allow participation in integrated activities?

Everyone's needs change throughout life; therefore assessment for people with developmental disabilities should be carried on periodically and lifelong if necessary.

Planning

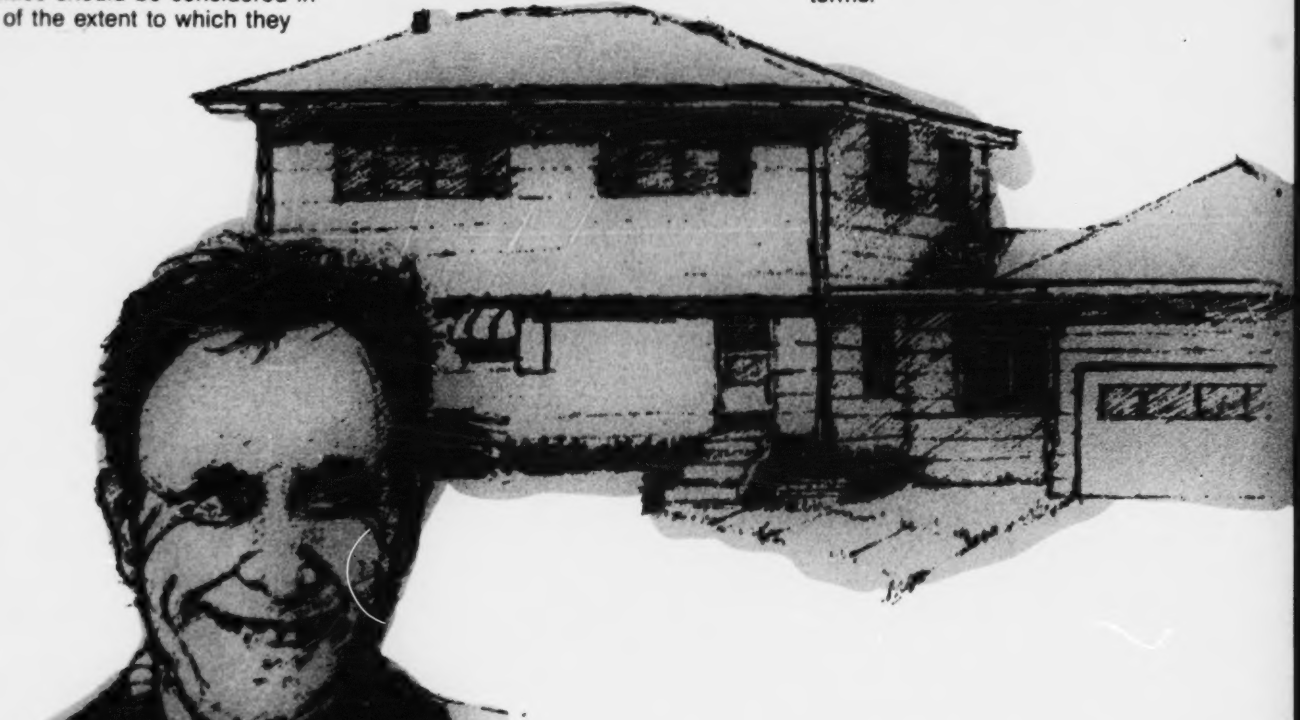
Planning is the setting of goals the individuals should achieve in order to reduce dependence on others and increase essential skills and behaviors that will improve their quality of life.

Planning includes three activities—developing plans, selecting services and arranging service delivery.

1. ***Developing Plans.*** The integration philosophy requires a different approach than the traditional way plans have been developed. The new kind of planning should provide a method for choosing outcomes that are valued by the individual and family.

Services in the Individual Service Plan (ISP) should describe what general supports the individual needs (in living arrangements, personal relationships, training or therapy, etc.) to improve community integration and quality of life. They should not be listed by facility labels, such as Intermediate Care Facilities-Mentally Retarded (ICF-MR) or Developmental Achievement Center (DAC).

The Individual Habilitation Plan (IHP) should include strategies to build and maintain community connections. It should also include the criteria to measure progress toward valued goals. Changes in the person's skills and behaviors should be stated in measurable or observable terms.



27

Examples of appropriate change statements or objectives for an IHP are:

- Within four months of this date, Jim will take no more than 30 minutes to set the table, appropriately and independently, with specified silverware, dishes and glasses.
- Within one year of this date, Nancy will lose 10 pounds by walking briskly in the neighborhood and using the exercycle for a total of four hours of exercise per week.
- By the next annual evaluation, Steve will be able to wash and dress himself in 45 minutes every morning with only verbal supervision.

2. *Selecting Services.* Planning also involves deciding what kinds of services are most likely to help individuals attain their goals. Rule 185 guidelines from the Minnesota Department of Human Services suggest that services need not be identified by labels (e.g. ICFs-MR, DACs, or sheltered workshops).(2) The integration approach to selecting services is to generally describe in the ISP the person's basic human needs—for a real home, education, employment, health care, personal relationships and social activities; and then to describe, in the IHP, the more specific arrangements, supports and strategies to meet these human needs.

An example of an appropriate description of a residential service for an ISP is:

Ann needs living arrangements that are the least restrictive possible. These arrangements should provide 24-hour supervision in typical housing (a single-family home, apartment, condominium or townhouse). The home should be in the Metro Area close to her family, to potential employment and to community services. She should have no more than one or two housemates because larger numbers of people distract and upset Ann and prevent her from relating to other people in socially appropriate ways.

When services are chosen, a high priority is to increase opportunities to expand the person's activities and experiences. Sometimes the person has lived in highly sheltered environments or has severe behavior problems. The person's opportunities to express preferences or to have experiences that most nonhandicapped people take for granted usually have been very limited. The team should start with what they know the person enjoys and what other people of the same age, but not handicapped, typically enjoy doing.

One such human experience is spending time with one or two close friends, at home, school, work or during recreation. Because people with severe disabilities may not be able to communicate these normal longings, or even seem aware of them, does not mean they do not exist. Yet making close friends and spending time with them is seldom considered as a specific goal for people who have severe multiple handicaps. Appropriate goals and services should reflect basic human needs and the person's known interests, and be typical for someone the same age as the individual.

3. *Arranging Services.* Planning also includes obtaining and authorizing services. In Minnesota, services provided to persons with developmental disabilities require contracts or written agreements between the county and the service provider. The county has the responsibility to see that the provider delivers the service as stated. The case management team has opportunities to seek quality community connections when arranging for all services. The team needs to make these aims clear to service providers. The role of team members in arranging services has exciting new possibilities that will be discussed later.

NOTES

1. Lyle Wray and Colleen Wieck. "Moving Persons with Developmental Disabilities toward Less Restrictive Environments through Case Management." *Strategies for Achieving Community Integration of Developmentally Disabled Citizens.* ed. K. Charlie Lakin and Robert H. Bruininks. Baltimore: Paul H. Brookes. 1985.

2. Minnesota Department of Human Services, Division of Developmental Disabilities. Rule 185 Discussion Papers: Series 1, Number 3. "Individual Service Plan." St. Paul, MN. 1986.

OTHER RESOURCES

1. "Moving Persons with Developmental Disabilities toward Less Restrictive Environments through Case Management." Lyle Wray and Colleen Wieck. *Strategies for Achieving Community Integration of Developmentally Disabled Citizens.* ed. K. Charlie Lakin and Robert H. Bruininks. Available for purchase from Paul H. Brookes Publishing Company; P.O. Box 10624, Baltimore, MD 21285. Call toll-free 1-800-638-3775 for credit-card orders. Cost: $26.95. Or available from lending library of the State Developmental Disabilities Program Office, 300 Centennial Building, 658 Cedar St., St. Paul, MN 55155; 612 296-4018 or 612 296-9962 TDD. Chapter 9 identifies the essential elements of community-based, client-centered case management systems and what changes are needed to strengthen the case management system.

ANOKA
WASHINGTON
DAKOTA

Eric

He has autism and is seventeen
Years old.

Ultimate functioning for Eric
Was learning how to put his
Hands to good use and
Appreciate his ability to
Control his behavior in a
Parttime job at a restaurant
Working with non-handicapped
People, rather than be taught
How to prevent self-injury by
Putting his hands in his
Pockets or by folding them
Without an opportunity to
Progress in the real world
Showing his ability to do so.

Eric thrives on going to the bank,
Meeting people, and talking about how
He controls his behavior at work.

Way to go, Eric.

Congratulations to his parents and
Employer.

Chapter 5

Monitoring, Evaluating And Advocating

This chapter continues the discussion of the five major functions in the casemanagement process. The last three steps are monitoring, evaluating and advocating.

Monitoring

Monitoring is the continual overseeing of both the person with developmental disabilities and the services to ensure coordination, continuity and appropriateness. Because the new integrated services are less restrictive and more informal, monitoring becomes especially critical.

1. *Coordination* refers to actions taken to make sure that the many services a person receives work together. One way to promote coordination is to have all service providers attend and participate in the annual evaluation conference for the person they are serving. This event allows providers to meet one another and to become more familiar with the person's performance in other settings. Providers also can learn each other's effective strategies for helping the person attain the ISP goals. The conference may also increase providers' willingness to accommodate to the requirements of other programs when conflicts arise among programs regarding strategies or scheduling activities.

> **B***ecause the new integrated services are less restrictive and more informal, monitoring becomes especially critical.*

2. *Continuity* implies that no unnecessary interruptions in services should occur as the person's needs change. If a person's needs are reviewed on a regular basis, when changes are indicated they can be made more smoothly. Services should be directed not only to present needs but to future and lifelong needs. But a single provider should not deliver all services to a person in an effort to ensure continuity.

3. *Appropriateness* means making sure a specific service is actually bringing the benefits sought. Periodic checks are needed. Changes in a person's circumstances (a new roommate, staff changes, family situations, illness) may change the kinds of services needed. Certain aspects of the service may have to be intensified or relaxed; new approaches or incentives may be needed.

Consistent and conscientious monitoring can do much to prevent very serious problems. But sometimes sudden, unforeseen or drastic changes, or the cumulative effects of a persistent problem, may cause significant difficulties for the person. Crisis intervention by specialists (behavioral, medical, therapeutic) may be needed. They can advise staff and families about preventive care as well as intensive remedies or long-range intervention. Crisis-intervention strategies should be continually monitored and should always begin with the least intrusive approach.

In monitoring, the case management team should actually visit the person's environment. That includes observing not only the person but also the attitudes and skills of the people who provide daily services to the person who is developmentally disabled.

Observing problems in the person's environment reduces the chance of blaming lack of progress on the person or the disabilities. Such knowledge provides a more hopeful outlook for the person's ability to grow and develop.

To help the team determine whether the services being received promote improvements in the person's quality of life, turn to the checklists in Appendix D, E and F.

> ***"The most dramatic shift in our way of thinking is the recognition that the social and physical environments are often a greater issue than abilities and disabilities."***
>
> *—Colleen Wieck*

Evaluation

Evaluation is a means to determine whether the individual's needs are being met (and goals in the ISP and IHP have been achieved).

The people involved in the evaluation are the members of the case management team—the person, family and case manager. In Minnesota, an annual evaluation conference is required by Rule 185. It determines whether the services have contributed to the ISP outcomes. Evaluation should measure how much the person has increased functional skills, improved behaviors, and reduced dependence on others. Criteria for measuring changes should be written into the Individual Habilitation Plan and providers should be held accountable for the results to which they have agreed. Therefore their presence at evaluation conferences is also necessary.

Improvements not only in the individual's personal status but also in community status, or integration, should be measured. These are measures of values important to every person—even those who cannot communicate this importance. These values contribute to the quality of life.

Measuring one's quality of life may seem to be too vague and subjective—not reliable. Dr. James Conroy, of Temple University, who has had many years of experience in such measuring, says that changes in a person's skills and behaviors "can be measured effectively and reliably." He says that no evaluation for quality "is complete (or even adequate) until it can demonstrate that service recipients are showing measurable gains."

For those who claim that such an evaluation process would be too costly, Conroy states that for evaluations that include "environmental assessments, plus family surveys, plus quantitative individual data on behavior, services, health and day programs, our costs have never exceeded $250 per person per year." He adds that outcome evaluation is possible and to be preferred, since it can incorporate not only growth in a person's particular skills and behaviors, but also "individual happiness and comfort, family satisfaction and increases/improvements in the person's acceptance, status and integration within our society."(3)

Another evaluation tool that measures the consumer's satisfaction with services is "A Normalization and Development Instrument" or ANDI.(4) It addresses such values as choice, equal opportunity and actual participation of adults in decisions about their own lives (control). Besides identifying changes in the person's status, evaluation includes gathering new information for further decisions.

Integration principles are leading to more-individualized, less-structured services. These new services will have fewer and less-standardized regulations. The integration perspective calls for new monitoring strategies that consider outcomes of services. Parent and citizen monitoring have been found effective in other states and are currently being developed in Minnesota. As more citizens are coming into contact with people with severe handicaps, their concern and influence over the quality of services is increasing.

Advocacy

Advocacy means working on behalf of people with developmental disabilities to see that their own preferences, civil and human rights are honored.

Society realizes that some individuals are unable to make their needs known or to exercise their basic civil and human rights. It further acknowledges that they need assistance over and above the needs of people who are not handicapped. For these reasons federal and state regulations provide formal advocacy procedures to protect the interests of people with developmental disabilities.

Examples of this statutory protection are found in the federal Developmental Disabilities Act, the Education of All Handicapped Children Act and the Social Security Act. In Minnesota's Rule 185, advocacy requires "protecting the rights" of persons receiving services and reporting their aggregate needs when appropriate services are not available. Revisions to Rule 185, administrative bulletins and training sessions are needed to better define this advocacy responsibility.

There are two kinds of advocacy. The first is "individual advocacy," which requires case managers to represent the best interests of the person and the family at all times. The second kind is called "class advocacy." This means representing the needs of people with developmental disabilities as a collective group or class.

One example of class advocacy is when case managers report to their counties what services are needed by their clients but are not available. Another example is when case managers try to alter policies and decisions within the service system and the community that present barriers.

Case management advocacy should seek to expand the choices and opportunities of persons with developmental disabilities to achieve greater independence, productivity and integration.

Team Communication

During the case management process, good communication among team members is essential. An open exchange can occur only when mutual trust has been established. Each party has unique information about the person's interests and behaviors, observed in different situations. Every attempt should be made to obtain information from the person whose future is being discussed. Families or service providers in close and continuous contact with the individuals often can translate their nonverbal reactions or responses into close indications of their feelings, preferences or interests.

Some families are reluctant to express their views because case managers and service providers are considered "professionals." Also, the traditional service system has confusing eligibility standards, complicated funding formulas and complex regulations. To allow more understanding and participation for families, the case management process needs to be simplified.

> *Families need not be "professionals" to determine which needs (for a home, education, work, friends, recreation) are not being met in a satisfactory way.*

The integration philosophy suggests that the process can be simplified if the case management team accepts that the person, as a human being, has basic needs that need to be met first. Families need not be "professionals" to determine which needs (for a home, education, work, friends, recreation) are not being met in a satisfactory way.

This approach allows each team member to contribute unique knowledge and skills. It requires the whole team to accept each member's contribution as an important part of the process. And each person's opinions and skills have value in building the connections that allow the individual to actively participate in the life of the community.

When the Process Is Unsatisfactory

Minnesota's Rule 185 gives recipients of case management services a way to seek changes if problems arise.(5)

The ***conciliation conference*** is an informal way for the individual and family to express dissatisfaction about their case management services or adequacy of other services.

The ***social service appeal*** is a more formal process. It usually covers problems such as a suspension, reduction, denial or termination of services or failure of the county to act within specified timelines. See Appendix G for a fuller description of these procedures.

NOTES

1. James W. Conroy, Celia S. Feinstein, and James A. Lemanowicz. "Principles of Quality Assurance: Recommendations for Action in Pennsylvania." Philadelphia: Temple University Developmental Disabilities Center/University Affiliated Facility. 1986.
2. "A Normalization and Development Instrument (ANDI) for Consumers." Lawrence: Kansas University Affiliated Facility. 1985.
3. Minnesota Statute, Sec. 256.045. "Appeals of Case Management and Related Services."

OTHER RESOURCES

1. "A Handbook for Members of Advisory Committees." 1983. Association for Retarded Citizens Minnesota, 3225 Lyndale Ave. S., Minneapolis, MN 55408. Free. Provides guidelines primarily for residential facility advisory comittees. Useful for families and providers.

Mary

She is legally blind, has
Mental retardation, a short
Memory span, cannot read, and
Lived in an institution for
Forty years.

Ultimate functioning for Mary
Began late, but not too late,
Memorizing cards picturing tasks
Of her first job in domestic
Services.

Within two weeks Mary had the
Task cards memorized, proving to
Herself that something associated
With success can be memorized.

She earned a well-deserved raise
In just six months
Ultimate functioning gave her a
Chance to become someone.

Way to go, Mary.

Chapter 6

The Case Management Team—A Partnership

In addition to understanding what case management is and how the process works, all those who participate in the process need to know what they are expected to do. They should know their rights and responsibilities in providing or receiving case management services. The principal participants include the local county social or human services department, the case manager, the person with developmental disabilities and the family. (Usually other professionals and service providers also are involved. This, chapter, however, will focus on the principal participants.)

The County: Administrator of Services

The Minnesota Department of Human Services (DHS) has delegated responsibility for providing case management to each county's unit of government that administers social and or human services.

This unit is usually the county board. As the administrator of case management services, it determines eligibility for case management, provides the services according to state laws and regulations, designates a case manager for each person eligible for services, and provides funding for services in the Individual Service Plan that are not the responsibility of other agencies. Other responsibilities include acting on appeals, providing public guardianship for wards of the commissioner of the DHS, and terminating services.

The county board reports every two years to the commissioner of the DHS on services licensed by that department. This report addresses the need for modifying, reducing or terminating use of existing services and for developing new services. The report should include information about what services are unavailable. This information should be collected from the Individual Service Plans (ISPs) of people with developmental disabilities for whom the county is financially responsible or for whom the county has agreed to provide services.

....All those who participate in the process need to know what they are expected to do. They should know their rights and responsibilities in providing or receiving case management services.

Problems That Arise

Certain problems usually found in most counties can interfere with their provision of case management. Most of these problems relate to a need for services exceeding a county's resources. Requests for services are subject to financial limitations of the state and county. Frequently, case managers' heavy case loads make it difficult for them to spend the time necessary for creative and individualized attention to all their clients. Other problems case managers have cited include the extra travel time needed when clients live in widely dispersed locations, especially in rural areas; the lack of available services; and the amount of time needed for reporting and other paperwork. Qualifications and training for case managers differ statewide; this also interferes with providing appropriate case management.

Attempts are being made to solve some of these problems. The state and counties are continually looking for supplemental funds to increase the number of case managers. Proposed federal amendments, such as "The Home and Community Quality Services Act," offer additional funds for case management. Advocacy organizations seek legislative and administrative solutions.

Meanwhile, the Minnesota Governor's Planning Council on Developmental Disabilities, in conjunction with several nonprofit agencies, funds demonstration projects to improve case management and other services. Two recent projects have developed computer technology to reduce the time needed for the administrative reporting and recording duties of case managers. Other projects of the Governor's Council include: training parents to be more active by assuming new responsibilities in the case management process, producing information for use by the case management team, and developing a model for monitoring services by independent teams of parents and the concerned public.

The DHS, the Minnesota Governor's Planning Council on Developmental Disabilities and the Minnesota University Affiliated Program (UAP) work cooperatively to improve case manager training. There is statewide involvement of the counties in these joint efforts to identify critical areas for training. The training models that are produced will reflect "best professional practice." This means that the ideas and methods used are those that are viewed by leading professionals as more effective in helping people with developmental disabilities lead more satisfying lives.

The Case Manager: Information Source and Team Leader

The case management process consists of five tasks: assessing, planning, monitoring, evaluating and advocating (see Chapters 4 and 5). The case manager's role in each of these tasks is primarily one of providing information, guidance and assistance to the individual with developmental disabilities and the family so they can make decisions, and obtain and evaluate services.

In accordance with the new integration perspective and Rule 185, this process promotes the empowerment of the person with developmental disabilities and the family as active decision-makers. And it's up to the case manager to create a supportive environment for meetings that allow opinions and choices to be expressed and honored.

Part of the case manager's responsibility is to collect current information, including diagnosis, personal history and the present status of the individuals and their environments, to help assess their situation. The case manager should directly observe and communicate with the individual in every service setting. These contacts provide random checks on the accuracy of reports from others.

Because this information helps guide decisions about the assistance the person needs, all members of the case management team need to have the same information. Therefore assessment information in the person's file should be available to the individual and the family, if they are the legal guardians. Sharing information also assures that it is adequate, accurate and relevant to the decisions that need to be made. If, previously, the information used to diagnose a person has been based only on I.Q. scores, level of retardation or other disability labels, and on failures in past performance, then the new approach to assessment, described in the previous chapter, should be used. "Personal Future Planning"(1) is an excellent strategy for this type of assessment.

The case manager should directly observe and communicate with the individual in every service setting. These contacts provide random checks on the accuracy of reports from others.

In any meeting of the case management team for assessment, screening or developing ISPs and IHPs, and for the annual evaluation conference, Rule 185 states that the case manager should convene and lead the meeting. Convening should include more than sending a meeting notice. It offers the case manager a chance to clearly and briefly explain the purpose of the meeting, the actions to be taken, the rights and expected roles of the individual and family as active decision-makers, and what records have to be produced (e.g., meeting record, ISP, screening form). Leading the meeting also gives the case manager an opportunity to create a supportive atmosphere, acknowledging the other team members as important to the case management process.

Prior to or at the beginning of the meeting, the case manager should give families informative materials, such as this booklet since most families may be unfamiliar with the process and new concepts of services. The case manager should also let the individual and family know of their right to determine outcomes and to request needed services even if they are not currently available.

The case manager should encourage the individual and family to voice their ideas throughout the meeting. It is also the case manager's role to make sure that the individual and family understand their right to appeal decisions at every phase of the process. They should be given information about the conciliation conference and the social service appeal. These procedures allow the person and family to appeal any perceived inadequacies in case management or other services.

The case manager should let families know that their opinions and decisions are valuable. Explaining the importance of their roles can give them confidence to exchange views freely, and may provide a less intimidating atmosphere for dealing with "professionals." This more open communication in the team process in turn creates more awareness of the interdependence of each party and builds effective teams.

The case manager should explain, as soon as possible, how services are changing from segregated and insulated services to community integrated services. The case manager should explain the benefits of the new individualized services and how the new services can be obtained. Making this publication, new videotapes and audiotapes available to families can make the case manager's communication more effective. The tapes can be loaned to families and shared when the family is together in the privacy of their home. Or they can be used before meetings in county offices that have equipment for viewing or listening to the tapes. This booklet can be given to clients to use for monitoring of services and for future evaluation conferences.

The case manager should promote full discussion of complicated issues, answer questions and raise questions when appropriate. When there is consensus on the individual's major needs, goals and services, the case manager should record them in the ISP.

> ***Every attempt should be made to help the person participate in decisions and to use what is known about an individual's likes and dislikes as a basis for selecting and arranging services.***

The case manager next must link the individual and family to appropriate service providers. If services do not exist or are unavailable at the time their need is identified, the case manager secures interim services, recording these as "temporary," and writes into the ISP the strategies and timetable to secure the agreed-on services. This process presumes that the case manager, acting for the county, will arrange for services or assist in the design and development of needed services when necessary.

> ***"Individuals are to be involved in determining their own destiny as much as possible; parents and guardians are to be involved . . . It is incumbent upon the case manager to facilitate this involvement."***
>
> *—Deborah Spitalnik*

Once the services (interim and actual) have been decided, the case manager authorizes them. Authorization requires the county to contract or write "purchase of service agreements" with providers who agree to deliver services consistent with the person's ISP. The new type of services still will require counties to have formal written agreements with providers. Providers are required to report to the county case manager at least quarterly on the person's progress toward the short-term objectives in the IHP as stated in Rule 185. The case manager should share these reports at the annual evaluation conference.

The Individual: A Key Role

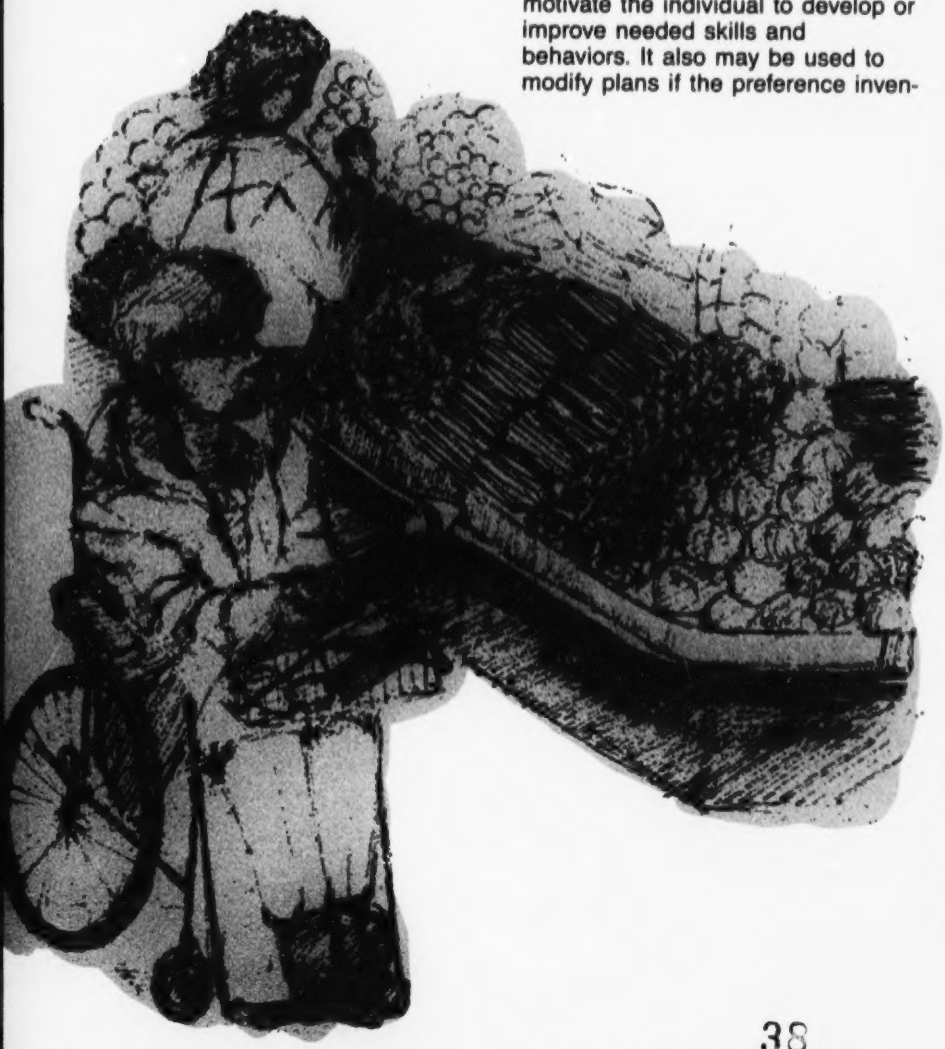
Earlier in this publication, the changes in beliefs about persons with severe handicaps were explained. Although historically, people who are developmentally disabled have not made choices, it is no longer presumed that they do not have this ability. Some adults with severe handicaps may have only slightly impaired decision-making ability. The total loss of rights and power to make decisions may be unwarranted unless the demonstrated need for protection is substantially more important for the person's welfare than loss of those rights. Then court action may limit those rights in some areas.

When individuals who are developmentally disabled are capable of making informed decisions about their needs and services, their ideas should be heard. The person's decisions take precedence over that of family unless the family is the legal guardian.

Minnesota laws protect persons with no family or friends to act on their behalf. Certain guardianship responsibilities for the individuals are assigned to a local county social worker. A person's case manager, however, may not also act as the guardian. In such situations a different social worker is assigned as the person's guardian. For more information about guardianship in Minnesota, see Appendix H.

How can other individuals, who cannot give adequate information about themselves or make informed decisions, participate in the process? The person should be present at all case management meetings unless medical reasons prevent this. Every attempt should be made to help the person participate in decisions and to use what is known about an individual's likes and dislikes as a basis for selecting and arranging services. Using a preference inventory can be useful.

The inventory is a collection of informal observations of what the person likes or dislikes in different environments: home, day program (classroom, job training site, cafeteria, field trip) and places where social or recreational activities take place. These observations are periodically recorded by people familiar with the ways in which the person indicates preferences for objects (clothes, food, furnishings, equipment), people, settings, activities, physical positions, communication, learning modes and expressions of emotion. Preference inventories should become more specific over time.



Ideally, preference inventories should be available before assessment, screening and development of a plan. The information can be used to identify incentives that would motivate the individual to develop or improve needed skills and behaviors. It also may be used to modify plans if the preference inventory suggests that earlier decisions are less satisfactory to the individual.

How to treat conflicts that arise if an individual's choices differ from those of the family or case manager will be explored later in this chapter.

As family members provide information, they may need to be somewhat assertive, because some case managers and other professionals still tend to dismiss some parents' claims about their son's or daughter's abilities or behaviors.

The Family's Role

Federal policy authorizes service providers to involve the individual and family in certain services. Minnesota's Rule 185 also specifically authorizes the family's participation in the assessment and planning for services. The family's involvement in the monitoring, evaluation and advocacy procedures is implicit but not specified. Other policies of Minnesota and its counties also encourage or authorize the family to take an active role in planning and making decisions about services. The family is a natural support system that should be recognized and incorporated into the goals and objectives of the ISP and IHP.

One of the family's major roles, especially in assessing needs and planning services, is that of information-giver. As family members provide information, they may need to be somewhat assertive, because some case managers and other professionals still tend to dismiss some parents' claims about their son's or daughter's abilities or behaviors. Families should try to be objective and open to new information about their family member.

They should be willing to accept documented reports about behaviors or skills they themselves may never have witnessed. Families also should share family problems that could affect their children's welfare, as long as confidentiality is assured.

Because the family is virtually the only life-long advocate the person with developmental disabilities is likely to have, laws involving families build on a natural role. Because of association with the person over time and a wide range of experiences, the family has, in most cases, comprehensive and in-depth information. The family also has unique insights about familial traits (inherited or cultural) which often can provide clues about the individual's temperament, coping behaviors, likes and dislikes. Sometimes these traits are assumed mistakenly to be caused by the person's disabilities.

For example:

> ***Nancy became extremely agitated every day at breakfast or when she was in crowded or even moderately noisy places. This behavior was attributed to her being severely retarded and having severe behavioral problems. A discussion at an annual evaluation conference brought out the information that one of the parents and a sister could not tolerate eating breakfast in the morning and also experienced stress in crowded or noisy situations. The parent and sister skipped breakfast and avoided or quickly removed themselves from the two types of conditions that they found stressful. Later, the staff allowed Nancy to skip breakfast and to have a mid-morning snack. They also avoided placing Nancy in crowded or noisy situations. The incidence of disruptive behavior decreased considerably. Nancy's environment was adjusted to accommodate to her.***

NOTES

1. Beth Mount. "Personal Futures Planning." West Hartford: Future Graphics, Inc. 1985.

OTHER RESOURCES

1. PACER (Parent Advocacy Coalition for Educational Rights). 4826 Chicago Ave., Minneapolis, MN 55417; 612 827-2966, V/TDD. PACER is a leading national resource for information about educational rights for students with all handicaps. It provides workshops for parents in every aspect of the educational system. It is one of the new computer resource centers in the country and has printed materials on a vast range of education issues.
2. "New Housing Options for People with Mental Retardation or Other Related Conditions: A Guidebook." 1987. Available from the Association for Retarded Citizens in Minnesota, 3225 Lyndale Ave. S., Minneapolis, MN 55408. Cost: $5 for nonmembers, $3 for members. Describes a variety of home-ownership models and funding possibilities; gives examples of actual arrangements in Minnesota and other locations and briefly discusses related supports such as guardianship, conservatorship and trusts to ensure future oversight.
3. Twin Cities Society for Children and Adults with Autism, 253 Fourth St., St. Paul, MN 55101; 612 228-9074. TCSAC also provides a wide variety of other information and supports for families.
4. MNASH Education Integration Committee, P.O. Box 1837, Pioneer Station, St. Paul, MN 55101. This committee offers a resource directory ($3.00) and free technical assistance to families seeking integrated education for their children.
5. "If Your Child Has a Special Need, So Do You: Pilot Parents Can Help." Brochure available free from Pilot Parents Minnesota, 201 Ordean Building, Duluth, MN 55802; 218 726-4745. Organization offering supportive networking among experienced and "new" parents of children with all kinds of disabilities.
6. *What Color Is Your Parachute?* Richard Nelson Bolles. Berkeley: Ten Speed Press. 1981 edition only. Available at some public libraries. This book is primarily a job-hunting manual. However, this early edition has an extensive checklist of some common traits, skills and interests that could be used as a starting point in developing preference inventories for people with developmental disabilities.

Paul

He has severe cerebral palsy.

Ultimate functioning for Paul
Was learning how to make it to
The top by carrying his own
Weight rather than being
Taught how to adapt to a
Lifestyle almost 100% dependent
On others.

After a year and a half of
Hard practice, Paul can carry
His body up and down fifteen
Stairs, around the house,
Make his bed, wash clothes and
Dishes, clear the table and
Empty wastebaskets.

Way to go, Paul.

Congratulations to his parents,
Brothers and sisters for taking
The time to show their love.

Chapter 7

Exploring New Roles

Enabling people with developmental disabilities and their families to participate in making decisions changes traditional roles. Until recently, the case manager and direct service providers have exercised primary control, especially in assessing need and planning services. As concepts of services change, some families have begun to take on a larger role. They ask for, find or even develop more appropriate services for their family members.

For example, a growing number of families with children in the special education system are taking advantage of PACER services. PACER is a Minnesota organization that provides parents with training in how to obtain their children's rights to appropriate education in the least restrictive environment.

In some states, families are beginning to explore home ownership by the person or the family. Using the team approach, some families and case managers in Minnesota have established homes for people with developmental disabilities. Medicaid waiver funds (Title XIX) pay for program staff and other support services. Supplemental Security Income (SSI) and Minnesota Supplemental Assistance (MSA) or similar combinations of financial assistance and other income pay for residents' food and shelter. Families have selected and purchased the houses and indicated the services and providers they prefer. A guide to help families use this strategy has been developed by the Minnesota Department of Human Services, and is published and distributed at cost by the Association for Retarded Citizens of Minnesota.

Another group of families has developed videotapes for the specialized training of staff who work with people with autism. The Twin Cities Society for Adults and Children with Autism offers the tapes and a guidebook for sale to service providers. These are just a few examples of the more active roles that families are taking in improving the futures of people with developmental disabilities.

The integration principles, which are changing the traditional service system, encourage the individual and family to take an active role in monitoring and evaluating services if they wish. This participation becomes more feasible as their roles expand in the assessment, planning and development of the Individual Service Plan (ISP) and Individual Habilitation Plan (IHP). Families may also spend some time observing and visiting the various service environments. In addition, measuring the individual's and family's satisfaction with services such as those described in Chapter 3, offer another way for families to participate.

> ***"Consumers are getting smarter about what is possible. For some parents, the move has been toward self-education. The field of developmental disabilities now has an ever-increasing number of parents who have become competent professionals in their own right. They speak articulately and loudly for their sons and daughters."***
>
> *—Edward Skarnulis*

A Delicate Balance

Selecting services requires a delicate balance between what is desired by any one party and what is possible. At these times, the family and case manager have to consider the choices of the individual and make decisions, using as the main criterion, "the best interests of the individual." Families and case managers must keep in mind that all human beings need to have some control over their lives. Displaying preferences, likes or dislikes is an important aspect of being human; it should be acknowledged to be as appropriate for persons with severe disabilities as for any other person.

Balancing each team member's roles and rights, however, can cause confusion, tension and, at times, conflict. Sometimes, a family or case manager may decide an individual's decision shows a lack of knowledge of serious consequences or risks; they may see that the person's experience in the community has been limited.

Other individuals with severely impaired cognitive skills may not be able to make complex decisions but may be able to indicate their preferences. Even those preferences may not be able to be met. Sometimes, however, a creative solution may take those preferences into account.

For example:

> ***Peter's family was supportive and close-knit. He expressed a preference for living arrangements that would allow him to leave his group home and live with any one of his sisters or brothers. But they all were unable to have him live with them because of inadequate space in their homes, heavy responsibilities for their own children, or their own or their spouses' inability to take on the***

amount of assistance needed by the young man.

Rather than completely disregarding Peter's obvious preference for closer contact with his siblings, an apartment was found for him near their homes. His new location provided opportunities for Peter to visit his brothers and sisters, invite them to his home and be included in their activities more often. At least in some part, his preference to be near his family was addressed.

Some families and service providers assume complete control over the lives of people with developmental disabilities. This approach has contributed to a distorted concept of them as human beings lacking any of the abilities, emotions, needs and interests of people who are not handicapped. Another effect has been to limit the person's opportunities to develop any skill in making choices. Then the lack of this skill is perceived as the absence of any desire, ability or potential to make choices. This perception in turn reinforces those families and service providers to continue total control over every aspect of the individual's life.

This approach is no longer tenable. Strategies for teaching people with severe disabilities how to make choices have been demonstrated and reported. (See Appendix I.)

Risk Is Inevitable

Another factor that has led to over-control by some well-meaning families and suppliers of services is their concern about the risks involved in allowing choices.

One way to consider this dilemma is to acknowledge that risk exists in any situation where choices are made. Some risks are very high but some may be worth taking. The high-risk areas involve decisions related to survival, vulnerability or exploitation of the person with developmental disabilities. If a person needs living arrangements that provide 24-hour supervision and assistance, allowing that person to live alone with only periodic supervision would be a high-risk decision. A family member or case manager redirecting that choice would be acting "in the best interest of the person."

This would not mean, however, that the person will never gain enough independence to live alone. The decision, may only be temporary. The individual's preference, in this case, should be used as a motivator to learn the skills needed to reduce the need for total assistance and presence of staff.

The low- or no-risk area is one in which people's choices will not seriously harm them physically or emotionally. Examples of low-risk choices might include selecting between two types of blouse or shirt to wear in the morning. It might be skipping a meal and later asking for a between-meal snack. A person may wish to stay home rather than go on an outing, or vice versa. Sometimes low-risk choices may have to be accepted over a period of time. For example, a person may want to use a heavy application of perfume or after-shave lotion, or wear clothes with clashing colors. Other people's reactions eventually can change the person's decision more readily than the advice of those who are "authority symbols."

No one operates absolutely free from risk. Some risk is inevitable for all of us and that includes people with severe handicaps. Mistakes can become the best teaching experience. The individual's preferences can be strong incentives to growth and development. Therefore a fine balance has to be achieved in both areas, high risk and low- or no-risk. When agreement about the areas in which the decision falls is difficult, it must be discussed as objectively as possible, including consulting with the individual. The preference inventory is useful if the person cannot easily communicate preferred choices at the time decisions are being made.

For example:

Terry was enthusiastic about sports and wanted only school classes that included athletic activities. He was offered several new opportunities to select and enjoy athletics during leisure time if he agreed to learn needed skills in other school subjects. He agreed and has joined an after-school community sports program which is currently a specialized program.

For example:

Frank got very excited by large trucks, and wanted to become a driver of a semi-trailer, or a firefighter who rides a fire engine. Frank's preferences were redirected to a volunteer job where he was able to help wash fire engines in a local fire station. His severe disabilities did not prevent him from partial participation in working around large fire trucks. The case management team helped him build a good community connection in his volunteer services. He has also formed a close association with one firefighter and his family.

Advocating Change

Advocacy is a natural role for families. They should let officials know what services or changes are needed. For example: Public funding provides minimal in-home and family support services. Administrators and public officials need to know that most families, willing to keep their children at home, need assistance. The people in power need to change funding methods to support families. Although the Education for All Handicapped Children Act, Minnesota's Family Subsidy Program and the Medicaid Waiver Amendment encourage families to maintain their children in less structured and less costly services, the funds available for family support and waivered services are a small fraction of the funds for services provided in a facility.

Individual and organized parents have been advocating changes for at least 35 years. Parent organizations have been effective in changing federal, state and county laws to improve the lives of people who are handicapped. One organization, directly concerned with the unique needs of people with severe and multiple disabilities, is The Association for Persons with Severe Handicaps (TASH). It is an international organization that has chapters in most states including Minnesota. Many of its founders and current leaders have directed or taken part in research, demonstration and publication of integration principles and practices in the United States and other countries.

Parents and service providers have found that joining advocacy organizations provides them with direction and assistance in communicating with those in power. They also are a source of current information about integration principles and about practices that have proven effective in developing the skills and behaviors their children will need to build quality community connections.

> ***"Family support is common sense. Family support is sound financial policy. Family support is reinforcing the family as the foundation of our society. Family support, in the best of systems, is the empowerment of families to (have) choices and control over their destiny."***
>
> *—Allan I. Bergman*

Traditional roles and responsibilities are changing as the importance of the individual and the family in the decision-making process becomes better understood and accepted. Families' willingness to become active team members must be based on confidence that their efforts will be fully supported. They must be encouraged to feel that their involvement is essential to the success of a consumer-oriented case management system.

A strong partnership among the members of the team provides a strong foundation for building community connections. Case management becomes the stable factor for families that facilities and buildings have symbolized for so long.(2)

NOTES

1. Deborah Spitalnik. "Elements for Consideration in Restructuring or Creating Case Management Services." Paper presented at a conference: "Case Management: The Critical Connection." St. Paul, MN. 1987.

OTHER RESOURCES

1. "Parent Case Management Program." This project trained parents to learn about the roles and responsibilities of case management and to take more active and informed roles as team members. Project resources include a 1,200-item library, a training package, model forms for an Individual Service Plan, respite voucher system and parent-county agreement. ARC Suburban, 14451 County Rd. 11, Burnsville, MN 55337; 612 431-3700.

2. "How To Get Services by Being Assertive: For Parents of Handicapped Children and Their Helpers." 1985. Coordinating Council for Handicapped Children, 20 E. Jackson, Room 900, Chicago, IL 60604; 312 939-3513. $6 per copy, greatly reduced price for orders of 30 or more copies.

3. Newsletters of interest to families and service providers are sometimes available free of charge. Some are sent only to members or by subscription. Most organizations will send a sample copy free to those who request one.

   - "DD Information Exchange." (Free) Metropolitan Council, DD Program, 300 Metro Square Building, St. Paul, MN 55101.
   - "Family Support Bulletin." (Free) United Cerebral Palsy Associations, 1522 K St. NW., Suite 1112, Washington, DC 20005.
   - "Connector." (Free) Minnesota Council on Disabilities, 208 Metro Square Building, St. Paul, MN 55101.
   - "National Spokesman." (Free) Epilepsy Foundation of America, 4351 Garden City Dr., Landover, MD 20785.
   - "Community News." (Free) Community Services for Autistic Adults and Children, 751 Twinbrook Pkwy., Rockville, MD 20851.
   - "News Digest." (Free) National Center for Handicapped Children and Youth, P.O. Box 1492, Washington, DC 20013.
   - "Independently Speaking." (Free) Metropolitan Center for Independent Living, 1619 Dayton, Suite 303, St. Paul, MN 55104.
   - "Report." (Free) National Organization on Disability, 2100 Pennsylvania Ave. NW., Suite 232, Washington, DC 20037.
   - "MNASH Messenger." Minnesota Association for Persons with Severe Handicaps, P.O. Box 1837 Pioneer Station, St. Paul, MN 55101.
   - "Newsletter." Metropolitan Association for Hearing Impaired, 4452 15th Ave. S., Minneapolis, MN 55407.
   - "Word from Washington." United Cerebral Palsy Associations, Governmental Activities Office, 1522 K St. NW., Washington, DC 20005
   - "TASH Newsletter." The Association for Persons with Severe Handicaps, 7010 Roosevelt Way NE., Seattle, WA 98115.
   - "Spina Bifida Newsletter." Spina Bifida Association of Minnesota, P.O. Box 29323, Brooklyn Center, MN 55429-0323.
   - "ARC Focus." Association for Retarded Citizens of Minnesota, 3225 Lyndale Ave. S., Minneapolis, MN 55408. Local ARC chapters are listed in some telephone directories.

Sheila

At the age of fifteen she became
A person with epilepsy. Within
One year memory loss began, a
Learning disability caused by
Anti-seizure medication.

Partial Participation for Sheila
Was learning how to adapt to
Her learning disability by using
A tape recorder in class to serve
As a backup for her memory.

During the first year of her
Learning disability, Sheila's
Grade point average fell from 3.10
To 1.68.

Because a teacher was able to
Identify her learning disability and
Sheila had the courage to use a
Tape recorder, her grade point
Average managed to reach a 3.0.

Her hope to attend college is not lost.

Way to go, Sheila.

Congratulations to her teacher.

Partial Participation affirms
Each person's right to
Adaptations needed
To participate in the same
Opportunities that everyone else
Uses to develop and become
Valued members of their communities.

44

Chapter 8

Using 'Regular' Community Resources

Because of the persistent, long-term efforts of parents, professionals and other advocates, a separate resource system has been built over time for persons who are developmentally disabled. Traditional beliefs identifying people with their disabilities fostered heavy reliance on the specialized system. As a result, use of specialized services replaced the generic community resources.

Specialized facilities serve only people with developmental disabilities or other handicaps. Such services physically and socially separate the person with severe handicaps from nonhandicapped people (other than family or staff) most of the time.

For example:

Eight years ago, Jon's family needed help. Jon was a hefty and outgoing 12 year old with severe mental retardation and cerebral palsy. His family had two younger children. But Jon's care took extensive time and effort. He could not communicate clearly or walk. He needed to be fed, bathed and dressed. Both his mother and his father developed back trouble from lifting him in and out of his wheelchair, bed and bathtub, and up and down the outside stairs. The parents never went out together because they could seldom afford the cost of trained sitters.

The help offered to Jon and his family was to place Jon out of his home. After a year-long search for a facility for Jon, he was placed in an Intermediate Care Facility for the Mentally Retarded located in another county. It was the only "facility" available. The family visited him only twice a month because of the distance to the facility. Relatives who frequently visited the family never went to visit him. They said seeing Jon among so many other handicapped youngsters would be depressing. (Jon, while at home, was just another member of the family whom they enjoyed.)

The facility cost included several services Jon did not need. Except for physical therapy exercises which his parents had provided, he had no major medical problems. Yet the facility standards required that nursing care and a dietitian, firewalls for the furnace room, a sprinkler system and other services be available to every resident.

Within a year of leaving the family home, Jon refused to respond to his name. He began to have violent temper tantrums and other behavioral problems. He still displays these symptoms.

If services had been considered in terms of family support rather than a "facility," Jon's needs and his family's could have been met. This approach could have provided an entry ramp for the family home, a bathtub lift, and a chair lift or ramp for the family van. His parents also could have obtained respite care periodically. Jon's specific needs could have been met more cost-effectively if he had remained at home. His strong identification as an individual and as a part of his family, and his family's need to keep him in the family were either ignored or considered unimportant in the traditional service system.

New Concepts in Services

The integration philosophy proposes meeting the person's human needs first. Its principle regarding family support is that services should supplement, not supplant, the family. When a family, alone. cannot cope with the child's needs because of the disabilities, assistance or services should be provided directly to the family in a way that allows the child to remain at home when this is in the child's best interests.

Another major change arising from integration principles is a move toward the use of "regular" resources. These are resources that nonhandicapped people generally use when they seek housing, education, employment, recreation and companionship. This change also means reducing reliance on specialized services, facilities, equipment and programs that are designed only for people with developmental disabilities.

> *"Regular" resources...are resources that nonhandicapped people generally use when they seek housing, education, employment, recreation and companionship.*

Generic, or regular, community resources are the usual services, settings and equipment available to all members of the community. Some are offered by the private sector (theaters, restaurants, clubs/organizations, churches/synagogues, stores). Others are run by government agencies (parks, social services, community centers, libraries). Still other resources are operated by both the private and government sectors (schools, sport facilities, employment, health care, housing, transportation). Other less formal types of help are provided by relatives, friends and neighbors.

As a rule, generic resources are available to all those who seek them. However, for most of history, people with developmental disabilities have not used generic community services because they lacked needed adaptations or modifications. This reason is no longer valid because there is ample information about ways to adapt regular environments so they can be used by people with severe handicaps.

Use of only specialized services casts people with developmental disabilities in devalued roles. Jon's relatives were overwhelmed by seeing only the disabilities of the group, not Jon. Separating him from the mainstream of the population ignored his need for self-esteem and family ties, friendships and acceptance as a valued member of his community.

The integration philosophy would not propose immediate and total reliance on generic services, or elimination of all specialized services. That is considered "dumping." Rather, families and case managers should begin now to adapt or modify both specialized and generic services to meet every need of the person.

Making the Transition

Many integration services are made possible by use of waivered services offered by Medicaid. Medicaid is a federal program that has been used in Minnesota and other states to pay for residential services in Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) and for habilitation programs in developmental achievement centers (DACs) for eligible people who have developmental disabilities.

As the unusual progress of people living and learning in less restricted arrangements became more evident, the federal government designed the waiver program. This allows Medicaid funds to be used for a wide variety of family and community services. These include family support, homemaker, habilitation, case management, respite care, and specialized vocational services, as well as supported living arrangements and minor accessibility adap-

tations to the home.

Families should know that Medicaid waivers are limited by the federal law. Each county is given only a few waivers each year. However, the county also has the responsibility to determine whether existing traditional services are still required and what new kinds of services are needed. If requests are not made for waivered services, the more restrictive, facility-dependent programs may be continued by the county. Brochures giving more information on waivered services are available from several Minnesota organizations.

For those who cannot obtain waivers now, the focus must change to modifying current specialized services to provide quality connections. For example:

> *Tom lives in an Intermediate Care Facility for the Mentally Retarded with 14 other people who have developmental disabilities. Classified as severely retarded, he also exhibits many challenging behaviors such as striking others, screaming and hallucinating both at the group home and at the developmental achievement center he attends. He is also overweight.*
>
> *At Tom's last evaluation conference, Tom's parents asked if he could be helped to get some physical exercise every day; their experience with Tom was that increasing his physical activity reduced the frequency and intensity of his behavioral outbursts. They suggested a brisk, 30-minute walk twice a day with one member of the staff. The facility representative immediately responded that there was no extra staff to give this kind of supervision.*
>
> *The parents suggested that the facility should find a volunteer who might walk with Tom. The response was that the facility's volunteers only came to celebrate birthdays once a month or to mend the residents' clothing. The parents suggested finding a different volunteer from a church or civic group. The staff said they wouldn't find one. The parents said they would be willing to pay a student or other community resident to accompany Tom on a daily walk. Staff said the facility was starting an aerobics class and would make sure Tom participated. They also agreed to seek a volunteer to walk with Tom. The case manager recorded this request and the facility's response.*

More opportunities for building community connections and individualizing services can be developed if the case management team becomes more persistent, and providers become more flexible, creative and accomodating. For example:

> *Lisa attends a developmental achievement center (DAC). She has been diagnosed as severely retarded and partially blind. Because she cannot walk, she uses*

a wheelchair. Her case manager suggested that the DAC find Lisa employment in the community. Lisa's mother and DAC staff were doubtful about Lisa's ability to work in the community. The case manager suggested three jobs in community businesses near the family home. With obvious reluctance the DAC staff visited two job sites and owners to explore the possibilities of employing Lisa. Both results were fruitless.

Lisa's mother accompanied the DAC staff on the third job exploration. She had changed her mind and her determination won over the employer. Lisa works two days a week for two hours each day repotting small plants in a greenhouse. She earns very little, but she is a wage earner. She tells her brother and sisters about her job every time she sees them. They work, too. Now she can identify with them.

All members of the case management team must insist on more individualized strategies from the specialized-service providers. Most often only higher expectations and a little extra time are needed for creative solutions when more funding is not available. The team and service providers should continually remember that Rule 185 specifies that services should provide the least restrictive settings that promote independence and community integration.

> *Community resources would afford many more opportunities for people with severe disabilities to observe others as role models, to have direct contact with them and eventually to develop acquaintance and friendships.*

The education sector may provide an example of what transition means in one generic service. Some school districts are trying to achieve the balance between generic resources and specialized services. Integrated education locates special-education students in regular schools, and special educators are present to support the regular teacher as well as the students who are developmentally disabled.

Thus, these students can attend many classes with other students and participate in nonacademic and some academic activities. Students with severe handicaps are able to ride the same school bus, eat in the same cafeteria during regular lunch periods and attend extracurricular events together. In these interactive situations, those with substantial impairments are also provided additional assistance by bus aides, teacher aides, peer tutors and others. Kids with handicaps go to the same schools as their brothers and sisters.

Local public schools can make the adaptations and modifications needed to accommodate the students with disabilities who live in the school district. This may require removing physical obstacles (adding ramps, elevators, accessible restrooms) as well as making necessary adaptations to programs (rescheduling buses or classes; hiring additional support staff; recruiting and training peer tutors). It may involve schools in advocacy. Educators can explain to regular teachers, students who are not handicapped and their parents why accommodations are needed and can discuss the benefits all parties will derive from integration. Other community resources can follow this example.

Benefits of Integration

Several reasons can be given for moving toward more reliance on regular resources and less dependence on specialized services. Most important are the benefits of such a transition to people with developmental disabilities. Total reliance on specialized services offers them few contacts with people of different ages. Community resources would afford many more opportunities for people with severe disabilities to observe others as role models, to have direct contact with them and eventually to develop acquaintance and friendships. At the same time the community develops awareness of the supports needed for the person to function on a daily basis and begins to respond to such needs.

The community also benefits from this kind of integration. It puts into perspective, and creates a better understanding of each person's own limitations. It is useful in teaching people to cope with differences, to accept people for their human value rather than base acceptance on appearance or labels. Frequent contact with individuals who have severe handicaps provides direct experience of their determination, loyalty and sense of humor. It increases opportunities to share, to make friends and to help. It provides diversity in the community. When people with developmental disabilities are part of the pattern, the fabric of community life is enriched and strengthened.

> ***"We must design schools, homes, workplaces, health care systems, transportation, and other social environments in such a way that they take in everyone. Our communities and our services must be pluralistic rather than exclusionary."***
>
> *—Douglas Biklen and James Knoll*

Creating Responsive Communities

Genuine integration does not happen spontaneously. Families, case managers, other service providers and advocates must take the initiative. Seeking to have regular community resources adapted is one place to begin. Community residents have to become aware that people with severe handicaps are a legitimate part of the community because they, too, are citizens. Setting people apart magnifies their differences. When people mingle together, differences in appearance, skills and behaviors become relative variations.

> *To supplement participation in community activities, the case management team and other service providers should help the person to develop his or her own personal support network.*

Gradually, as people with developmental disabilities connect with their communities, their integration will be taken for granted. Contact and understanding of this historically excluded part of society is the best foundation for creating an informed and responsive community.

To prepare communities to become responsive, families, service providers and advocates should develop specific ways to involve people with developmental disabilities in the daily life of the community. The person should be partially or fully engaged in activities that are typical of that age group in the community. Such activities may include swimming in a pool when other people are using it, attending the neighborhood school, receiving on-the-job training, working during the same hours and in the same locations as other employees who are not disabled, or eating in restaurants or school cafeterias when others usually eat.

Several strategies can be used to help people participate to some extent in typical community activities. Good resources are ***Community-Based Curriculum Instructional Strategies for Students with Severe Handicaps***(1) and ***Community Integration Strategies: A Functional Approach to Programming.***(2)

Personal Support Networks

To supplement participation in community activities, the case management team and other service providers should help the person to develop his or her own personal support network. This network ideally would include three or four people other than the person's immediate family or staff who provide services. These people befriend the individual; they also can act as mentors, a popular concept in women's groups and among business people.

Members of this personal support network can be sought out specifically. Their participation also can arise naturally from involvement in the same community activities. Potential network members can be found at religious services or social activities sponsored by churches and synagogues, in hiking or walking clubs, YMCA/YWCA classes, basic adult education classes, civic organization events, Red Cross volunteer activities, regular Scout troops, community center or playground activities, integrated camping sessions, sports or booster clubs and school clubs. A list of community organizations has been suggested by John McKnight. (See Appendix J.) The extended family also offers possibilities for members of the personal support network—cousins, uncles, aunts, nieces, nephews, in-laws or grandparents.

At least some members of the personal support network should be in the same chronological age range as the person with developmental disabilities. Network members should be made aware that others in the network are also willing to spend time with the person. This helps to alleviate the concern that such a relationship may require more time or responsibility than an individual wishes or is able to contribute.

Contact may be as little or as much as people find comfortable. It may consist of simple acts, on a regular basis, such as greeting the person on his or her arrival at a

> ***"The idea of personal support is really quite simple—a group of people upon whom an individual depends—family, friends, fellow students, co-workers, members of the congregation, bowling partners, and so on. The network of people who ask us questions, give advice, act on our behalf, invite us out, give us leads for jobs, help fix up the basement; things which are freely given as part of living, not as an activity for which people expect to be paid."***
>
> *—Canadian Association for Community Living*

meeting, class or session, of exchanging a little conversation, of sitting with the person when refreshments or breaks occur, of introducing the person to others. The member of a personal support network may offer to drive the person to the place where they both will be going, or to physically assist the person to participate in an activity. It may involve inviting the person home, attending a movie or a neighborhood softball game, or having a meal together. One could help the person shop for clothing or groceries, or enjoy walks together.

Contacts by a member of a personal support group can be as frequent or as seldom as the member can commit to—once a month or a few times a year. The important factor is that the personal support group members ***want*** to do this because of a genuine interest in the person. This interest is most likely to assure that the association will be sustained.

It is up to the case management team and direct service providers to find, orient and help network members in their efforts. Family members or staff can inform the network member about what motivates and interests the person, the best methods to communicate or effective ways to assist the person who has severe handicaps. Help may consist of family or staff accompanying the person and network member on initial activities. If and when it seems appropriate, the family member or staff should gradually fade from the relationship. If, however, his or her presence is a condition for the association to continue, then the family member or staff should become a passive member, allowing the two main people to build their relationship.

Ideally the personal support network should grow to include more people. Continually seeking use of new community resources should provide new members for the network and should help to maintain a circle of three to four friends if others drop out.

Developing a more integrated service system is an important change in our society. It will take hard work and some time. As people with developmental disabilities take their rightful places as active members of their communities, the whole society will be benefit.

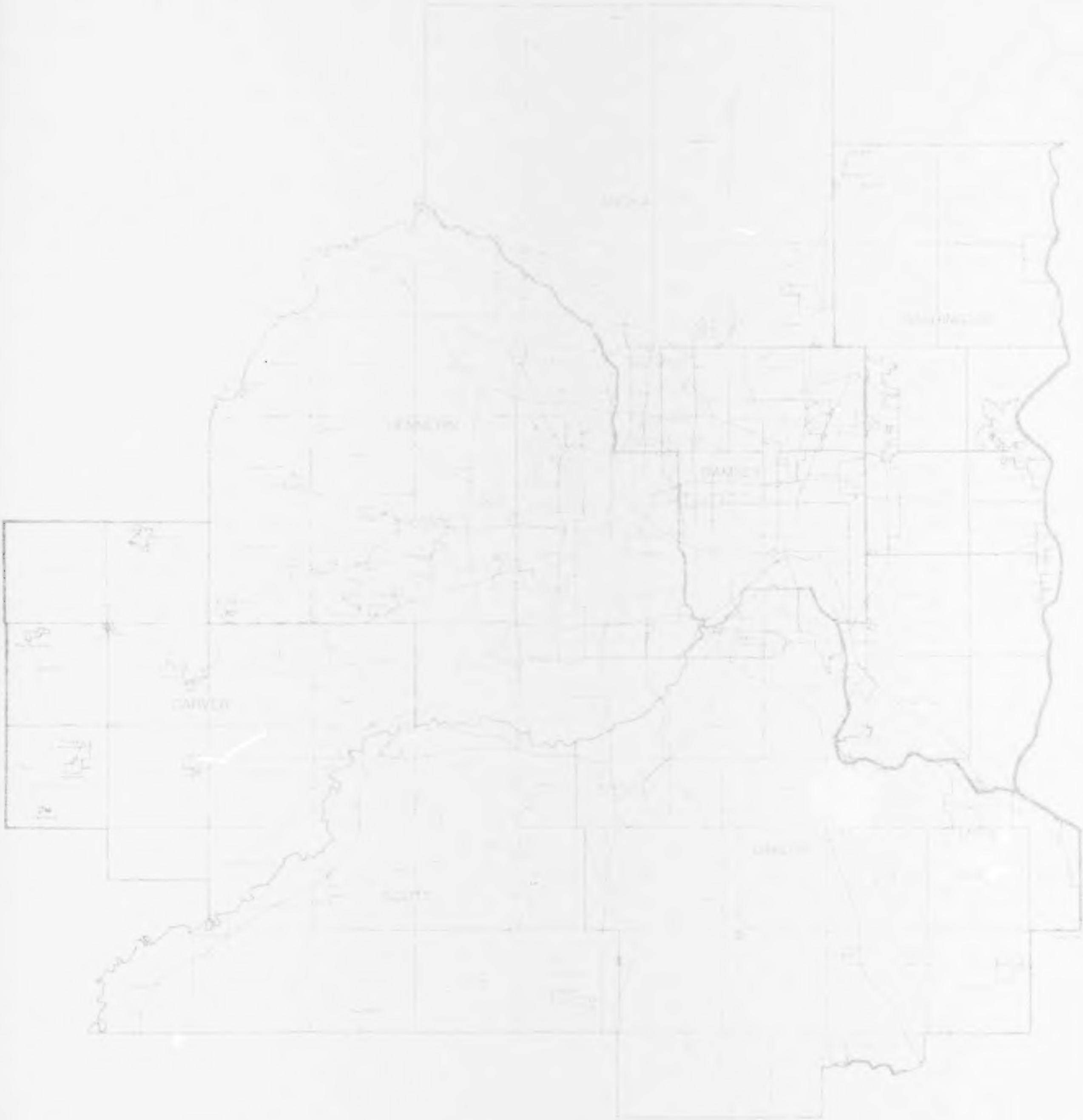
NOTES

1. Mary A. Falvey. *Community-Based Curriculum: Instructional Strategies for Students with Severe Handicaps.* Baltimore: Paul H. Brookes. 1986.
2. Government Training Service, Developmental Disabilities Program. "Community Integration Strategies: A Functional Approach to Programming." St. Paul, MN. 1983.

OTHER RESOURCES

1. Free brochures on the waiver are available from: ARC Minnesota, 3225 Lyndale Av. S., Minneapolis, MN 55408; 612 827-5641 and ARRM, 1885 University Av., St. Paul, MN 55104; 612 644-8181.
2. *The Activities Catalog: An Alternative to Curriculum for Youth and Adults with Severe Disabilities* and *A Comprehensive Guide to the Activities Catalog.* 1987. Barbara Wilcox and G. Thomas Bellamy. Available from Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285. Call toll-free 1-800-638-3775 for credit card orders. Cost: $29.95.

   Illustrated catalog suggests over 100 activities and subtasks in the areas of leisure, personal management and work for use by parents and service staff; guide explains use of the catalog activities as a comprehensive system in a particular service or in structuring a well-rounded lifestyle for anyone who is severely disabled. Excellent.
3. *New Life in the Neighborhood.* Robert Perske. Nashville: Abingdon, 1980. This publication skillfully portrays how neighborhoods are enriched by the *integration* of people with disabilities.
4. "Promoting Community-Based Services: Implications for Program Design, Implementation and Public Policy." Michael D. Powers. Journal of the Association for Persons with Severe Handicaps (JASH). 1986. Vol. 11, No. 4, 3090-315. This article describes five community-based projects that use integration practices, training, consultation and evaluation. Uses technical language.


ANOKA
HENNEPIN
RAMSEY
WASHINGTON
CARVER
SCOTT
DAKOTA

This Creation of God

Sitting alone in the reverend's
Office, her fingers crossed,
Hoping that her prayer will be
Answered. She wants more than
Anything to assist in church
Services.

The reverend arrives. Tension
Begins as he is gently trying
To explain how it would be best
To set aside her goal, pointing
Out how some parishioners will
Be distracted during services
By the complications of her
Disability — clonic seizures.

She can't hold back the tears.
This creation of God wants
So very much to fulfill her
Goal. She's grown tired of
Just doing things that
Persons with developmental
Disabilities are allowed to do,
Rather than what she wants.

Silently she ponders the
Questions. "Would God be
Distracted by a person with a
Disability?" "Would God prevent
Me from obtaining my goal?"

She musters enough courage to gently
Explain to the reverend that God knew
All along that she would have a disability.
That God would encourage, not prevent
Her, from obtaining the goal.
That God would reach out to parishioners,
Calling upon them to treat her as they
Do all others.

Her words were heard. A program was
Designed to teach her lessons on church
Services. The reverend called upon
Parishioners to respect her determination
To seek and fulfill a meaningful goal.

The principle of natural proportion was
Applied. God must have smiled.

The principle of natural proportion says
That persons with developmental
Disabilities should regularly interact
With more non-handicapped people than
Handicapped people approximate to that
Ratio in the total population.

Chapter 9.

Achieving An Integrated Society

> ***"Clearly there is a trend toward ever smaller numbers of people congregated together in residential, vocational and educational environments. We have moved from a period when people were both physically and socially separated from the rest of society to more physical and social presence and participation in the fabric of our society. These concepts are occurring at a variable rate in different parts of the county, but the trend seems inexorable."***
>
> *—Edward Skarnulis*

Social change is not always smooth. As in the change from the segregated institutional system to the insulated facility-dependent system, the transition to integrated services requires major system changes. One change relates to getting into practice what is expressed in current law.

For example, federal reviews of state special-education systems check on progress of school districts toward use of "least restrictive environment" or the inclusion of students with handicaps in programs with their fellow students who are not handicapped. The federal audits revealed that states are not in compliance with this federal standard, yet there is no discernible major change in segregated practices among the nation's school districts.

Other laws, such as Title XIX of Medicaid, must be amended. Then home and community-based services will not be so limited and require a waiver or "special permission," but become as free a choice as ICF-MR services.

Federal and state legislation concerning vocational rehabilitation and vocational education services has required inclusion of people with severe handicaps for some time. Nevertheless, the number of people with developmental disabilities who have been able to obtain these services is still small. To correct this inequity the proportion of funding for vocational training and employment in community businesses should increase and funding for facility-based services should be reduced.

Other Barriers

There are other barriers that delay development of an effective integrated service system. One is the resistance to changing from facility-dependent services to the more individualized arrangements. A lot of money and loyalty is now invested in specialized facilities in terms of buildings, land, equipment and jobs. A large constituency is opposed to reducing, or eliminating these facilities. It frequently includes some families whose sons or daughters currently use these services; boards of directors of facility services; and some county commissioners, state legislators and employees connected with large residential facilities, developmental achievement centers and sheltered workshops. The opposition of this group adds to the difficulty of acquiring legislative authorization and adequate funding during the transition period, and slows the move to integrated services. The concerns of those groups should be addressed in order to assure a fair and gradual transition to home and community quality services.

> *There are other barriers that delay development of an effective integrated service system. One is the resistance to changing from facility-dependent services to the more individualized arrangements.*

Concern about the quality of services and ability to monitor them in a more individualized service system is an issue frequently raised by some who oppose less use of facility dependent services. While centralized services may be easier to measure, their monitoring has been less than satisfactory. Current evaluation methods focus on the services rather than on the effects of those services on the people who receive them.

Phrases like "quality control" and "quality assurance" are used repeatedly in regulations, policies and the literature referring to services. Such measures of quality have included the number of hours that services are provided, the qualifications or number of staff who provide the services, the type of equipment or materials used, the size of rooms where services are provided, the amount of money spent for services, and license or certification requirements.

> *...Services are only the means to achieve an end. Service standards should be directly related to measuring quality outcomes for the person receiving the service.*

Admittedly, these elements are important in measuring the quality of services, but services are only the means to achieve an end. Service standards should be directly related to measuring quality outcomes for the person receiving the service. The integration principles translate into standards for services and *outcomes.* However, to apply standards that measure service effectiveness, a new kind of training is needed. And families should support the provision of this training for case managers and other service providers.

A New Kind of Training

Different job descriptions and qualifications are needed by case managers and others in order to obtain and evaluate services that assure integration. A new orientation, regarding values, a change in attitudes and expectations, understanding new concepts of service, designing strategies for planning services and evaluating outcomes, and keeping up with new information are all factors that must be addressed in developing preservice and inservice training of case managers and other service providers.

- ***A Framework of Values.*** Terms such as "normalization," "individualization," and "community integration" have been used for about two decades. But for persons with severe handicaps the reality these terms imply is still the exception rather than the rule. To check this claim, see how many of the integration principles listed in Chapter 2 are found in traditional, facility-dependent services. (Also see Appendix K.) Case managers and service providers need to use a framework of values that addresses the individual's (and the family's) quality of life. These values should emphasize the individual's right to make choices and should lead to the creation of living arrangements, education, employment and recreation that increase independence, productivity and community integration.
- ***Attitudes and Expectations.*** Emphasis on the client's handicaps should be reduced. Focusing on the person's humanity will build more positive attitudes. Expectations should reflect a belief that all people, regardless of the severity of their handicaps, can live in an integrated society, given proper support. Training should include real stories about the dramatic improvements that have taken place in the skills and behaviors of persons who moved from large facility settings to integrated environments, such as those reported by Baker and Salon(1) and those collected and published by the Pennsylvania Developmental Disabilities Council.(2)
- ***New Concepts of Service.*** The traditional definition of services, with its dependence on specialized facilities that provide prepackaged programs to their clients, must be reconsidered. Exemplary integrated services in Minnesota and other states should be identified and studied. ***Services should be redefined as individualized arrangements (personal assistance and environmental adaptations) that will best support the person to live a satisfying life integrated in the community.*** These arrangements currently may combine specialized and regular community resources, with more reliance over time on using regular resources that are supported or adapted.
- ***Assessment and Planning.*** Case managers should learn how to lead the case management team in using new assessment strategies. Service providers should also use these methods. They should learn how to identify basic human needs and support the strengths of the individual and the family, through preference inventories, personal support networks and personal futures planning.

  Planning strategies will be different too. Improving a person's quality of life will include making community connections by arranging integrated housing, education, employment and social activities. The team will need to learn how to translate quality-of-life goals into outcomes that can be measured. Training should include information and practice in recognizing that nontraditional community resources may be opportunities for peoples with severe handicaps to participate in events or activities involving nonhandicapped people.
- ***Monitoring and Evaluation.*** Recent federal laws require proof of the benefits of services for which funding is provided. Evaluation includes accurately measuring and documenting what the person can do before and after a period of time in which a service has been provided. Therefore, case managers who authorize services and staff who directly provide

them must learn to select and use appropriate measurement tools. Currently, the majority of such people lack the technical skills to measure changes using data collected by frequent observation. Training that develops reliable evaluation skills is needed.

- ***Integration Resources***. This booklet names both strategies and literature that reflect advanced professional ideas. Many more areas of integration practices still remain to be developed. It is essential that case managers and other service providers become more familiar with several major, reliable sources that provide state-of-the-art information and training. These sources may include cross-discipline literature, professional organizations and their publications, seminars, conferences or membership services.

The new training for case managers, other professionals and practitioners should be statewide, be consistent in value orientation and reflect the best professional thinking. This training should be formal, direct and systematic. Preservice, professional training, including practicums or internships, should be available in the state's universities and colleges and should reflect state-of-the-art theories.

Continuing education or inservice training for case managers or paraprofessionals also could be offered by area vocational technical institutes, institutions of higher education, the Minnesota Department of Human Services, other relevant state agencies, or some coordinating group. It should be provided by professionals who themselves are knowledgeable about recent developments across all service sectors. "State-of-the-art technology should be presented to inspire creativity and hope in the case managers . . . . ."(3)

Less-formal educational offerings should supplement formal training. Informal training may offer certain advantages. Higher-education and state-agency training procedures are fairly rigid because of the time required to add or change curriculum content or to obtain funding. Informal training can be planned and executed much more quickly. Such training is available at national, state and local conferences, workshops, seminars, institutes and forums usually offered by consumer advocacy groups or professional organizations. These events may bring a wide variety of speakers from different disciplines or service sectors. Often, the broad range of information and materials represents the latest in the field of developmental disabilities.

> *It is essential that case managers and other service providers become more familiar with several major, reliable sources that provide state-of-the-art information and training.*

Another way for case managers to keep current with new breakthroughs across all service sectors is to join a network of diverse county or regional professionals. These groups may meet regularly to share information monthly or quarterly. Knowledgeable speakers can be invited and common issues can be discussed.

Individuals with severe handicaps should participate in some way in these training sessions. Recently Emily, an adult who is developmentally disabled, participated in a workshop in Minnesota along with her attendant. The workshop was designed to teach participants how to use a value-based approach to evaluate services used by people with developmental disabilities. Those present discussed the use of typical names used in Minnesota for residential facilities, day training programs and sheltered workshops.

Emily said she disliked the house she lived in being identified as "Sunshine House" instead of as Emily's home or by a street address like other houses on the block. She expressed her humiliation at having to work in a "sheltered workshop" instead of a regular place of employment as her sister and brother do. She resented being spoken to as if she were a child or not being addressed at all while staff talked about her in her presence. The person who accompanied her, the other participants, as well as the workshop presenters all remarked on their heightened sensitivity to the values discussed as the result of Emily's participation in the workshop. They realized how such names emphasize the differences, the separation and the devaluing of people who use the services.

Counties and other service employers have the obligation to provide incentives and opportunities for inservice training for case managers and staff. This means paid time off should be given for staff participation in both formal and informal training. Training requires the need for financial assistance from federal and state levels also. Staff members who extend their training beyond the minimum requirements stated in regulations, or who apply their training in ways that are of outstanding benefit to their clients, should be acknowledged individually and publicly.

Barriers for Families

Other problems that hinder movement toward integrated services involve families of persons with developmental disabilities. They include the following.

1. ***Lack of information***. Many families do not have adequate or accurate information about the move

toward more effective services. Their primary information sources, the case manager or direct service providers, may not have the information or may give inaccurate, biased or conflicting views on integrated services.

Several local and national publications carry information about new and successful integration services. These include publications of consumer advocacy organizations and government agencies. They also provide news about current programs, research and governmental policies. Some of these publications focus specifically on people with severe handicaps rather than on people with all kinds of handicapping conditions.

Other excellent sources of information for individuals and families as well as professionals are the conferences, workshops and seminars mentioned earlier. Minnesota is particularly rich in the number and quality of these events presented several times a year by state or local organizations. These groups compete to obtain speakers who include well-informed parents and noted professionals who are leaders in the integration movement. Becoming a member of an advisory committee of a public or private agency or organization for people with developmental disabilities provides another source of current information for families.

> *Thinking of integration services as similar to resources that their nonhandicapped children use (to get suitable living quarters, education, adult education or employment) may help parents get over their uncertainties.*

Individuals who are developmentally disabled and their families should seek several information sources. With varied sources, families will gain a more accurate and comprehensive picture. Their increased knowledge also should lead them to expect higher standards of training for case managers and people who provide services.

2. ***Fear or Uncertainty about Change.*** Often older parents have seen so many kinds of services in their lifetimes that they become skeptical when changes are proposed. Families satisfied with current services are especially prone to resist substantive changes in those services. They may view the coming of less-structured services, and their own emerging roles as more active decision-makers, with uncertainty. They may lack confidence in changing a highly technical, complex but relatively stable system for something new.

Thinking of integration services as similar to resources that their nonhandicapped children use (to get suitable living quarters, education, adult education or employment) may help parents get over their uncertainties. Case managers are responsible for arranging the more technical support that families and their children with severe handicaps need. This help includes finding providers who will develop individualized living arrangements, integrated schools, adult training, vocational training and employment, and leisure-time activities. The case manager also assists families by securing the authority and funding for these arrangements.

3. ***Lack of Family Resources.*** Many younger parents face a quite different obstacle. While they maintain their children in the family home, have free public education and may even have some family supports, their main barrier to learning about new services is lack of time and money. Many families have to give so much extra time and energy just to care for the daily

needs of their children that they are unable to devote any more. Individuals and families often do not have enough money to cover the cost of publications or to attend conferences or workshops.

Some informational materials may be obtained free if one writes and requests a single copy. Other publications are available, free, on a lending basis from agencies or organizations. Some conferences, workshops and similar events provide care for children and free registration or reduced fees for persons who are developmentally disabled and for parents. A few organizations annually sponsor two or three individuals or their parents to attend such events. A sponsorship usually provides partial costs of registration fees, travel, hotel costs and sitter expenses. Families should inquire whether child care and subsidies are available as soon as announcements of events are sent out.

Current Information Is Vital

Individuals with developmental disabilities, their families, case managers and all other service providers should have an interest in what is happening in the field. The more the information spreads, the better are the opportunities to anticipate problems that changes may bring. No one is asked to accept change without questioning its impact on the lives of persons who are severely handicapped or their families. Issues that need additional clarification should be identified and discussed. Informed discussion and negotiations, rather than resistance and confrontation, provide a more productive environment during transition periods.

The transition from "facility-dependent" services to integrated services is already under way. Increasing numbers of parents and professionals:

- Are aware nationally of the integration philosophy, its principles and practices.
- Accept this trend toward integration.
- Are developing the competencies to put these principles into practice.
- Are organizing the community to be supportive.
- Are monitoring the effectiveness of the new services.
- Already are making needed improvements.

Families and case managers who read this booklet have already completed the initial step—becoming aware of the integration philosophy, its principles and practices. Acceptance may come slowly. The new information presented here and in the Appendices offers a means to start. Families, case managers and other service providers can use it to assist the person with developmental disabilities to achieve community status and personal satisfaction, and experience a better quality of life.

Those who do so may be rewarded by seeing individuals with severe handicaps progress in ways most people did not believe possible. The ultimate benefit, however, will come to individuals with severe handicaps as they grow in self-esteem and exercise choice, experience friendships and connect with their communities.

NOTES

1. Milton J. Baker and Rebecca S. Salon. "Setting Free the Captives: The Power of Community Integration in Liberating Institutionalized Adults from the Bonds of Their Past." *Journal of the Association for Persons with Severe Handicaps*. 11, No. 3. Seattle, WA. 1986.

2. "A Story That I Heard." Pennsylvania Developmental Disabilities Planning Council. Harrisburg, PA. 1987.

3. Deborah M. Spitalnik. "The Case Manager Role and the Training of Case Managers." Final Report: National Conference on Social Welfare. Indianapolis, IN. 1981.

OTHER RESOURCES

1. *Parents Speak Out: Then and Now*. H.R. Turnbull and Ann P. Turnbull. 1985. Columbus: Charles E. Merrill Company. Available from the lending library of the State Developmental Disabilities Program Office, 300 Centennial Office Building, 658 Cedar St., St. Paul, MN 55155; 612 296-4018 or 612 296-9962 TDD. Parents who have been leading advocates for improving developmental disabilities services express viewpoints in 1978 and again in 1985. Traces changes in lives of their children and in their own opinions. This is a very readable book and one with which parents can readily identify.

2. *Staff Development in Mental Retardation Services: A Practical Handbook*. James F. Gardner and Michael S. Chapman. 1985. Baltimore: Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285. Call toll-free for credit card orders: 1-800-638-3775. Cost: $21. Also available for Twin Cities residents only from the lending library of the Metropolitan Council's Developmental Disabilities Program, 300 Metro Square Building, St. Paul, MN 55101. 612 291-6364.

3. "Community Living 2000: A Time of Change, A Time of Challenge." Available from the Canadian Association for Community Living, G. Allan Roeher Institute, Kinsmen Building, 4700 Keele St., Downsview, Ontario M3J 1P3. This publication is the five-year agenda for CACL. It provides specific objectives the organization hopes to accomplish by the year 2000. Its simple, direct approach should excite and challenge American readers.

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Integration Test for Organizations Serving People with Developmental Disabilities

Appendix A

Seven Quality-of-Life Indicators*

Age-Appropriate

- Activities/tasks would be appropriate for nondisabled peers.
- Staff model appropriate adult behaviors (address people as adults, use age-appropriate reinforcers).
- Decorations and materials are appropriate for nondisabled peers.
- Schedule and routine are based on schedule of persons who are not disabled.

Productivity Measures

For Those Working:

- Number of hours worked by week/month/year.
- Wages (hourly/piece rate).
- Changes in wages over time.
- Length of time on job.
- Income covers his/her living needs.

For Those Who Are Not Working:

- Number of hours of volunteer work.
- Contribution to home and community.

Independence Measures

- Activities lead to personal growth, development, and personal satisfaction.
- A means of communication exists to allow daily interaction with primary people (speech, signing, adaptive devices).
- A means of mobility exists to move about home and community environments.
- Services are as least intrusive as possible.
- Reduction in need for services over time.
- Reduction in cost of specialized support or training.

Functional Measures

- Tasks and activities are relevant to daily life and use real materials.
- People are taught skills to live on own: how to spend their money, how to prepare food, clean house and shop.

Integration Measures

- Amount of time spent in integrated settings.
- Use of generic resources (transportation, parks, recreation, library).
- Number of interactions with nonhandicapped peers.
- Number of people with disabilities is less than 3% of total people in setting (such as work force, school, and recreation).
- Opportunities for friendships with nonpaid, nondisabled peers.
- Support occurs in heterogeneous groupings.

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*The Governor's Planning Council on Developmental Disabilities, St. Paul, Minnesota, May, 1987

Choice and Decision-Making

- Participation in decisions about home, choice of location, furnishings, and decor.
- Participation in decisions about use of personal income.
- Lifestyle choices encourage wellness—nutrition, weight, smoking, stress relief, emotional support, and appearance.

Appendix B

Developmental Disabilities Regional Policy Plan*

A. **Availability** is the measure of the supply and scope of appropriate services.

Guideline 1. Counties and other public jurisdictions, such as local health districts, school districts or vocational rehabilitation districts, should take primary responsibility to develop, provide or obtain adequate numbers and type of integrated community-based services for all individuals as soon as their needs are identified. Nonretarded persons who are developmentally disabled should be included in this responsibility.

Criterion 1. Periodic reviews of the service system by such jurisdictions should be carried out at least every three years to determine if changes are warranted in the array, eligibility for, capacity and quality of services.

Criterion 2. Subsequent changes in service should be based on these reviews and the cumulative data on the individual needs of a jurisdiction's clients rather than on what the service system currently offers.

Criterion 3. All persons with developmental disabilities should be included in service need assessments by counties and other jurisdictions, whether they are in state hospitals, in the natural home, or already in the service system.

Criterion 4. Adequate prevention services to avoid or ameliorate developmental disabilities should be offered in the region's service system.

Criterion 5. Planning to meet changing needs shoujld reflect familiarity with advances in service technology.

Criterion 6. Local planning should document citizen participation that includes elected/appointed officials, clients and/or their families, providers and other interested citizens.

B. **Accessibility** is a measure of whether services are provided so that consumers can easily find and use services.

Guideline 2. Counties and other jurisdictions should eliminate physical, attitudinal, regulatory and financial barriers to services.

Criterion 1. Generic and specialized services should be provided in settings with accommodations accessible to individuals with mobility, sensory or learning impairments.

Criterion 2. Since transportation is a key factor in using community services, public transportation should provide appropriate accommodations and adequate capacity for persons with severe handicaps using a variety of approaches. Expenses for specialized transportation should be an allowable cost if needed to access services.

Criterion 3. Regulations should allow purchases and maintenance of high-technology equipment such as computerized communication and prosthetic and educational devices that make possible contol of one's personal environment and access to services.

Criterion 4. Regulations should not constrain but should support use of generic resources when they provide the least restrictive alternative appropriate for an individual. Affirmative-action policies should, in fact, ensure the human and civil rights of persons with developmental disabilities to seek access to community resources.

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*The Metropolitan Council (1985) Service System Characteristics, Guidelines and Criteria

Criterion 5. Fiscal policies or incentives should not preclude individuals from obtaining the least restrictive services appropriate for them.

C. **Acceptability** is a measure of the degree to which services promote genuine opportunities for community integration, self-directed choices and reduction of dependency.

Guideline 3. A comprehensive array of community services should afford persons who are developmentally disabled use of the same resources as, and regular contact with, nondisabled citizens.

Criterion 1. Services should provide many opportunities for individual choices and options.

Criterion 2. Services should never be totally segregated in their physical settings nor prevent one's regular interaction with nonhandicapped people.

Criterion 3. The service system should include both formal and informal support networks.

Criterion 4. public and private service providers should assume responsibility for promoting public education about the advantages of community integration for the whole community in a manner that minimizes negative reactions from the general public.

Criterion 5. Service providers should be accountable for reducing their clients' dependencies in terms of quantitative or qualitative measures.

Guideline 4. Case management is an essential key to ensuring that the services selected for consumers result in their increased ability to participate, even partially, in community life.

Criterion 1. Case management should be comprehensive and include lifelong planning, obtaining, providing or developing individualized services and monitoring client outcomes from services provided.

Criterion 2. Case managers should keep the consumer's needs paramount and select and monitor services that assist consumers to grow in their ability to make decisions and express their preferences.

Criterion 3. Resources for case management should be adequate to recruit, train and retain case managers who meet competency standards related to developmental disabilities and commensurate with mandated responsibilities.

Criterion 4. Case management caseloads should be allocated on the basis of clients' levels of need with a maximum ratio of 1:25 for individuals who are severely handicapped.

D. **Continuity** is a measure of how services are provided to assure that the earliest intervention and uninterrupted support is available as needed over the lifetime of persons with developmental disabilities.

Guideline 5. A lifelong planning perspective should be the basis for selecting present and future goals and interim services needed by individuals with severe, chronic disabilities.

Criterion 1. Lifelong planning should begin at birth or as soon as a disability is suspected or identified.

Criterion 2. Lifelong planning is not static but is subject to continuing revision whenever the major needs of an individual change.

Criterion 3. Lifelong planning should include only goals that reflect client choices and that are directed to achieving present and future skills that are valued by clients, their families and society, are age-appropriate and are critical to functioning as a visible and participating member of the community.

Criterion 4. Public and private service policies should promote movement of individuals to the least restrictive setting needed.

Criterion 5. As consumers move through the different jurisdictions that provide services, transition should be facilitated by establishing joint responsibilities among agencies for planning, service funding, referral and followup without major interruptions in service provision.

Criterion 6. Direct provision of all major services to an individual by a single provider is not acceptable as a means to ensure continuity of services.

E. **Cost** is a measure of fiscal responsibility and cost-containment practices.

Guideline 6. Funding policies should address client outcomes and provide fiscal incentives to use the least restrictive services that appropriately meet an individual's needs.

Criterion 1. Costs should be reimbursed only for services that meet individual needs, incorporate the principles that derive from the normalization philosophy and document client outcomes.

Criterion 2. Fiscal incentives should reward service providers who contain costs while offering effective programs.

Criterion 3. Fiscal policy should promote a gradation of intervention that supplements what families can provide. Fiscal policy should support, not supplant, families. Fiscal policy should not result in serious financial burdens on families. When families maintain care of their developmentally disabled children at home, fiscal incentives should provide income-tax credits, financial subsidies, respite care, etc.

Criterion 4. Prevention services should be given high priority in budgeting decisions since numerous studies have reported their cost-effectiveness.

Criterion 5. Cost savings for a community-based service system can come from reallocation of funds from the institution-based services as they are phased down, using the least restrictive options available, promoting opportunities for employment of persons with developmental disabilities and changing fiscal incentives which restrict use of less costly, but more appropriate, services.

Criterion 6. Cost savings can be realized by fostering a competitive market where new service providers (including generic service agencies) are encouraged to enter the system.

F. **Quality** is a measure of whether all services in the system contribute to a quality of life valued by the person. Quality services assist each and every person with developmental disabilities to exercise choices on a daily basis; to establish meaningful, personal relationships with nonhandicapped as well as handicapped people and to develop and maintain a positive self-image.

Guideline 7. Quality services should be comprehensive and flexible enough to address the wide variety of needs of all persons with developmental disabilities.

Criterion 1. A comprehensive developmental disabilities service system should serve not only individuals who are mentally retarded but also individuals with other categories of developmental disabilities.

Criterion 2. Consumers' needs and preferences should take precedence over service rules, organizational practices and fiscal policies that unduly restrict consumer choices.

Criterion 3. Public and private service providers should take responsibility for developing environments and practices that allow consumers to make choices, seek satisfying relationships and develop a positive self-image.

Criterion 4. Consumers, parents/guardians and case managers should request service providers to be able to document the specific means to enable consumers to make their own decisions.

Criterion 5. Quality services should keep current with advances in technology and should exceed relevant governmental regulations since these represent minimum standards.

Criterion 6. Since mastery of advances in service technologies is central to the provision of effective services, it is incumbent upon service personnel to acquire the skills necessary to assure successful client outcomes.

Criterion 7. Quality assurance mechanisms in the developmental disabilities service system should include external as well as internal monitoring of the civil and human rights of persons receiving services. Participation of the general public, as well as those with specific interests, on program advisory, human rights and ethical practices committees provides a more balanced perspective regarding individual rights and program practices.

Guideline 8. In order for consumers to have a quality service system there must be adequate capacity to meet identified needs of the residents in the region who are developmentally disabled.

Criterion 1. Public and private service providers should make the development of adequate service capacity a high priority.

Appendix C

A Statement in Support of Families and Their Children*

WHEREAS:

All children, regardless of disability, belong with families and need enduring relationships with adults;

and

States and agencies have traditionally not supported the role of families in caring for children with developmental disabilities;

THEREFORE:

THESE PRINCIPLES SHOULD GUIDE PUBLIC POLICY TOWARD FAMILIES OF CHILDREN WITH DEVELOPMENTAL DISABILITIES...AND THE ACTIONS OF STATES AND AGENCIES WHEN THEY BECOME INVOLVED WITH FAMILIES:

Every child should have the right to a permanent home and a stable relationship with one or more adults.

When states or agencies become involved with families, permanency planning should be a guiding philosophy. As a philosophy, permanency planning endorses children's rights to a nurturing home and a consistent relationship with adults. As a guide to state and agency practice, permanency planning requires family support, encouragement of a family's relationship with the child, family reunification for children placed out of home, and the pursuit of adoption for children when family reunification is not possible.

Family supports should build on existing social networks and natural sources of support.

As a guiding principle, natural sources of support, including neighbors, extended families, friends, and community associations, should be preferred over agency programs and professional service. When states or agencies become involved with families, they should support existing social networks, strengthen natural sources of support, and help build connections to existing community resources. When natural sources of support cannot meet the needs of families, professional or agency-operated support services should be available.

Family supports should maximize the family's control over the services and supports they receive.

Family support services must be based on the assumption that families, rather than states and agencies, are in the best position to determine their needs.

Family supports should support the entire family.

Family support services should be defined broadly in terms of the needs of the entire family, including children with disabilities, parents, and siblings.

Family support services should encourage the integration of children with disabilities into the community.

Family support services should be designed to maximize community integration and participation in community life for children with disabilities.

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*Center On Human Policy, Syracuse University, 724 Comstock Av., Syracuse, N.Y., 13244-4230, 1986

When children cannot remain with their families for whatever reason, out-of-home placement should be viewed initially as a temporary arrangement and efforts should be directed toward reuniting the family.

Consistent with the philosophy of permanency planning, children should live with their families whenever possible. When, because of family crisis or other circumstances, children must leave their families, efforts should be directed toward reuniting the family.

When families cannot be reunited and when active parental involvement is absent, adoption should be aggressively pursued.

In fulfillment of each child's right to a stable family and an enduring relationship with one or more adults, adoption should be pursued for children whose ties with their families have been broken. Whenever possible, families should be involved in adoption planning and, in all cases, should be treated with sensitivity and respect. When adoption is pursued, the possibility of "open adoption," whereby families maintain involvement with a child, should be seriously considered.

While a preferred alternative to any group setting or out-of-home placement, foster care should only be pursued when children cannot live with their families or with adoptive families.

After families and adoptive families, children should have the opportunity to live with foster families. Foster family care can provide children with a home atmosphere and warm relationships and is preferable to group settings and other placements. As a state or agency sponsored program, however, foster care cannot guarantee children the continuity and stability they need in their lives. While foster families may be called upon to assist, support, and occasionally fill in for families, foster care should not be viewed as an acceptable alternative to fulfilling each child's right to a stable home and enduring relationships.

(Note: The principles are reprinted from a statement developed at a Policy Institute in June 1986, sponsored by the Center on Human Policy's Research and Training Center on Community Integration, located at Syracuse University in New York. The Policy Institute included parents, people with disabilities, professionals and state and national leaders committed to community integration.)

Appendix D

Options Policy on Quality of Life*

Introduction

The mission of Options in Community Living is to provide support and coordinate services to enable adults with developmental disabilities to live on their own in small, integrated community settings. The agency works with people to help them make their own choices and reach their own goals, with support available as often and for as long as it is needed.

Because our clients rent their own apartments which are not subject to licensing, any government regulations, or agency control, Options felt a responsibility to develop quality-of-life standards that apply to people who live in apartments or other similar community residences. We maintain that the expectations for quality of life for persons with disabilities should be the same as those for other members of the community. Support must then be provided on an individualized basis to help our clients achieve these standards.

The purpose of this document is three-fold. First, it serves to provide staff with standards for evaluating an Options client's well-being and for identifying areas where intervention is needed. Secondly, it provides the agency with guidelines for determining which individuals or groups are best served by this service model. These standards are not intended to be used as entrance criteria, but rather as a general framework for assessing community living needs.

The third purpose is to communicate to our consumers, their families, advocates, and professionals the principles that guide our services. We encourage open dialogue with our consumers and other interested parties about these principles and how they are implemented.

The policy addresses nine major aspects of community living. Each area is divided into two sections: 1) a list of those conditions that we feel must exist to ensure that people are not at risk in the community, and 2) a list of further conditions that Options will actively promote to help its clients achieve a valued lifestyle. It is anticipated that some people will need intensive and long-term support to maintain these standards.

A final comment must be made about the implementation of this policy. We believe that the responsibility for quality of life is shared by service providers, the consumer, and significant others. Options' services are voluntary and we will actively promote, but cannot enforce, these standards. We respect the right of our consumers, with support from their families and advocates, to assume responsibility for their life decisions.

I. Autonomy/Choice

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has opportunities to make decisions and express preferences in all areas of life. The right to make these decisions shall be respected by others in the person's life (e.g. service providers, parents, roommates). The person also has the right to refuse interventions initiated by providers.

2. The person has methods of expressing preferences and a method of acting upon these preferences in all areas of life. For example, a person who has a physical disability and is nonvocal might use a communication board to express preferences and have a personal care attendant to act on those preferences. Preferences can be expressed in nonverbal ways, such as by a change in behavior.

3. The person has access to information and experiences that assist the person in making decisions about his/her life.

4 The person has people in addition to service providers for support and information needed to make decisions about his/her life (e.g. family, friends).

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*Options in Community Living, Inc., 1954 E. Washington Av., Madison, WI 53704. Copyright 1987

II. Personal Income

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has a stable source of income that covers basic living needs, including shelter, food, transportation, clothing.
2. There is effective management of this income to ensure that basic needs are met. (Support can be provided when needed through a double-signature bank account, representative payee, or assistance with budgeting.)

B. Conditions that will further promote a valued lifestyle:

1. There is sufficient income for items and activities that enrich one's life experience, such as vacations and other leisure activities, home decorations, and items that enhance one's personal appearance.
2. The person is able to participate as fully as possible in decision-making about the use of personal income through the development of money and budgeting concepts and values that encourage financial responsiblity.
3. The person can maximize income through wise investments and purchases, and through subsidies for which the person is eligible.
4. The person has a means of earning income through employment as a supplement to or in place of government benefits.

III. Housing

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has housing that meets community building codes, is secure and has adequate heat, water and electricity.
2. The person has the basic furnishings necessary for daily living, including a bed, chairs, table and lighting.
3. The person lives in a neighborhood where s/he feels safe and where there is access to needed resources.

B. Conditions that will further promote a valued lifestyle:

1. The interior and exterior of the home is maintained in a safe, clean and attractive fashion.
2. The person is able to exercise control over the home environment, including the choice of location, personalized furnishings and decor, and control of temperature and lighting.
3. The home furnishings are attractive and complete.
4. The person is able to have maximum influence over his/her housing situation through such means as participation in a tenant association, cooperative housing or home ownership.

IV. Physical and Mental Health

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person's health is maintained through adequate nutrition, exercise, safe behavior, medical monitoring, and appropriate medications when needed.
2. The person receives prompt and up-to-date treatment for physical and mental health problems.
3. The person employs a personal care attendant if his/her physical disability limits the person's ability to provide self-care.

B. Conditions that will further promote a valued lifestyle:

1. The person has established relationships with and easy access to health care providers (e.g. physicians, nurses, dentists, counselors and therapists) who know the person and monitor his/her health needs on an ongoing basis.
2. The person's lifestyle encourages wellness. For example, the person eats nutritious meals on a regular schedule and maintains an appropriate weight; does not smoke; does not drink in excess or use drugs; has coping mechanisms to relieve stress; has people to provide emotional support.

V. Safety

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. Potential dangers in the person's environment are minimized. For example, his/her home is free of fire hazards and is locked and secure; the person does not walk alone on dark streets at night.
2. The person receives prompt and appropriate emergency services when needed, such as police, fire department, ambulance, crisis line.

VI. Appearance and Hygiene

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person minimizes health-related problems through adequate personal hygiene and clothing choice that are appropriate for weather conditions.
2. The person maintains acceptable hygiene and appearance so as not to restrict where s/he can live, work and socialize.

B. Conditions that will further promote a valued lifestyle:

1. The person has a choice of attractive clothing for different occasions.
2. The person maintains his/her hair in a manner that is becoming.
3. The person's hygiene and appearance serve to enhance self-esteem.

VII. Relating with Others

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has the means to communicate on a daily basis with primary people in his/her life. (This may include speech, signing and adaptive devices.)

2. The person has support people, including Options staff, with whom s/he is able and willing to maintain contact.

B. Conditions that will further promote a valued lifestyle:

1. The person has the means of communicating in such a way that encourages interactions with other members of his/her support system and community (e.g., clarity, assertiveness, appropriate affect).

2. The person has supportive relationships with family members that encourage independence.

3. The person has relationships with friends and peers that provide companionship, intimacy and support.

4. The person has the opportunity to responsibly engage in sexual relationships and marriage based on his/her personal beliefs and values.

5. The person's relationships include people who are nondisabled.

VIII. Meaningful Activities

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has a daily routine that is designed around his/her needs and capabilities and that resembles as closely as possible a typical adult routine. Such a routine is likely to include vocational, domestic and leisure activities.

B. Conditions that will further promote a valued lifestyle:

1. The person's activities provide opportunities for personal growth and increased life satisfaction.

2. The person receives wages for work.

3. The person takes part in culturally valued leisure activities, such as parties, trips, concerts and shows.

4. The person's activities take place in community settings that are integrated with nondisabled people.

5. The person has the means of developing and achieving short-term and long-term goals (e.g., vocational planning, vacations, retirement).

IX. Mobility

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has the means to move about his/her home and community environments to the extent necessary to satisfy basic needs.

B. Conditions that will further promote a valued lifestyle:

1. The person has physical access to a wide range of community resources for work, leisure, shopping, etc. Modes of transportation can include bus, car, bike, walking, vehicles equipped for wheelchairs.

2. The person, when needed, has adaptive devices that will enhance mobility, such as a cane, motorized wheelchair, three-wheel bike.

Appendix E

Quality Assurance in Community Mental Retardation Programs*

Definition of Quality:

The definition that follows is intended to provide a point of reference for designing and managing community mental retardation programs. It is also intended to provide a foundation for assessing and evaluating these programs. The numbered statements below describe the majority of conditions that, if present in community mental retardation programs, are likely to indicate high quality. These were derived from the work of major accrediting bodies and are intended to be subject to quantitative assessment (though they are not themselves necessarily assessment standards). Hyphenated statements following many of the numbered statements are included to illustrate the meaning of the numbered statements. They do not comprehensively define it.

Optimal quality in community mental retardation programs is best evidenced by client development, growth and satisfaction resulting from service delivery. Service systems are most likely to attain optimal quality when:

1. CLIENTS ACHIEVE MAXIMAL GROWTH AND DEVELOPMENT as evidenced by:
   - improved adaptive behavior
   - enhanced personal and social development
   - increases in independent behavior
2. CLIENTS ARE SATISFIED, evidenced by:
   - personal contentment; happiness
   - the presence of warm relationships (i.e., positive relationships with people in the community)
   - participation of clients and families in public review of service delivery
3. CLIENTS HAVE OPPORTUNITIES TO EXERCISE CHOICE IN ALL LIFE DECISIONS
4. CLIENTS PARTICIPATE FULLY IN ALL ASPECTS OF SERVICE DELIVERY by:
   - serving as members of boards and committees
   - participating as members of their own interdisciplinary teams
   - having opportunities for preplacement visits to assure full participation and informed choice
5. CLIENTS ACHIEVE FULL CITIZENSHIP IN THEIR COMMUNITIES by:
   - valued social participation in community affairs
   - having maximal opportunities to exercise the rights and responsibilities of citizenship
   - receiving advocacy services as needed or requested
6. CLIENTS' SERVICES ARE PLANNED AND IMPLEMENTED IN A COORDINATED FASHION by:
   - establishing an interdisciplinary team, including appropriate professionals; the client and his or her parent, friend or advocate; service and disciplines relevant to identifying the client's needs
   - identifying programs to meet documented needs, regardless of immediate availability
   - the assignment of a single person responsible for coordinating and monitoring the implementation of each client's individual plan
   - implementing needed programs in the least restrictive setting
   - developing an individual program plan for each client composed of goals and objectives developed by an interdisciplinary team in accordance with assessed needs
   - ensuring that each client's program plan is reviewed by an interdisciplinary team at least annually
7. EACH CLIENT RECEIVES THE FULL ADVANTAGE OF APPROPRIATE GENERIC SERVICES BEFORE SPECIALIZED SERVICES ARE USED
8. CLIENTS ARE SERVED IN THE LEAST RESTRICTIVE MANNER APPROPRIATE TO THEIR INDIVIDUAL NEEDS

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*Pennsylvania Department of Public Welfare (Mental Retardation Bulletin 99-86-08)

9. CLIENTS ACHIEVE FULL SOCIAL AND PHYSICAL INTEGRATION

10. CLIENTS' HEALTH AND SAFETY ARE FULLY ASSURED by:
    - guaranteeing that all personnel serving clients are licensed, certified or registered in accord with applicable laws and regulations governing services to the general public
    - guaranteeing that each service component is licensed, certified or approved as required by the appropriate state or federal authorities

11. FAMILIES AND ADVOCATES HAVE AN ACTIVE AND VALUED ROLE IN ALL ASPECTS OF SERVICE DELIVERY

12. AN INFORMED AND ACTIVE CITIZENRY SUPPORTS AND MONITORS SERVICE DELIVERY. This is achieved when:
    - fraternal, civic and social organizations include persons with mental retardation as valued members
    - business and industry take affirmative steps to employ persons with mental retardation
    - programs of community awareness foster acceptance of persons with mental retardation and facilitate their integration into the community
    - nonpaid personal relationships are fostered
    - all significant decision-making processes and service programs are open to full appropriate public review
    - community leaders and other citizens are formally recognized for their participation and support of new program developments

13. COMPETENT PERSONS ADMINISTER AND PROVIDE SERVICES. This is accomplished by:
    - identifying prerequisite skills and abilities
    - supporting systematic programs of in-service training and career development
    - establishing working relationships with human resource training programs
    - establishing relationships with colleges and universities

14. ANNUAL EVALUATION OF EACH COUNTY MENTAL RETARDATION PROGRAM IS CONDUCTED in order to assess:
    - the design of the system
    - approaches to solving problems
    - degree of integration with ongoing programs within the system
    - resolution of conflicting policies and practices
    - resolution of unnecessary duplication or uneven distribution of services
    - the need to simplify and combine administrative, operational and funding procedures
    - clients' needs in order to establish priorities
    - performance against stated goals and objectives

15. POLICIES AND PROCEDURES ARE STRUCTURED TO TAKE FULL ADVANTAGE OF EXISTING COMPETENCE AND EXPERTISE IN ORDER TO PROPAGATE BENEFIT TO OTHERS (CROSS-FERTILIZATION) by:
    - expressing all policies, procedures and evaluation results in common (non-technical) language
    - arranging for evaluation by professional and nonprofessional peers who are not involved in that county's service delivery system
    - openly sharing all descriptive and evaluative information with all participants in the community mental retardation system
    - arranging for regular and systematic consultation by persons familiar with other community mental retardation programs

Appendix F

The 'Why Question' in Educational Programs for Students Who Are Severely Intellectually Disabled*

The report by Dr. Lou Brown and associates recommended criteria to be used when deciding the content of instruction for students with developmental disabilities. The following material adapts these criteria so they may be applied to other services as well as to education.

The **content** of instruction should be:

- needed now or in the future in order to live in an integrated society,
- preferred by the individuals,
- valued by parents and the community,
- chronologically age appropriate, and
- functional (i.e. so essential an action that, if the person cannot do it, someone else would have to do it for the person).

The content should also address skills and behaviors that improve the individual's personal satisfaction, physical well-being and community status.

An integration approach emphasizes not only **what** services should teach, but also **how** services are provided. The "how" or strategies we use have several dimensions:

- who teaches the content
- where teaching occurs
- when it occurs
- what materials are used.

Who refers not only to program personnel and parents but also to whomever else a person with severe handicaps comes in contact with. Parents and staff are always symbols of authority because in their roles they most often are directing or supervising persons with severe handicaps. In segregated or insulated services, the person's chronological-age peers are other handicapped people.

A primary way of learning in childhood is by imitating the actions of others. As people grow to adulthood they find other means to learn. The person who is a severely limited learner is almost totally dependent on the imitation model. Therefore expanded association with and imitation of persons of their own chronologicasl age, who are not handicapped and who do not represent authority figures is considered an excellent way of learning appropriate behaviors and skills and a good integration practice.

Where teaching occurs is another important factor in acquiring appropriate skills and behaviors needed in an integrated society. Although some highly technical methods exist, few parents and service personnel know how to teach skills and behaviors so that persons with severe impairments can transfer what they learned in one setting to another similar setting or situation.

Integration principles propose teaching skills and behaviors in the natural setting where they will really be used. For example, training for job skills in a segregated or insulated facility does not effectively prepare a person to deal with interruptions or problems that may occur in a real job situation where other employees are not handicapped. The natural setting also offers others in the community opportunities to become aware of the many common human qualities of persons with severe handicaps that are more important than their limitation.

Toddlers and school-age children who only use "special facility" playgrounds lose the opportunity to associate with their nonhandicapped peers. Parents who accompany their nonhandicapped children to playgrounds or come to the school functions miss an opportunity to get to know or see children with severe handicaps as children who love to play or attend school or as having common human traits. Those parents may be the public officials and administrators, teachers, bus drivers, police officers, landlords, etc., of today. Their children will be taking on those roles in the future. The impact of having integrated settings is beneficial for both those who are severely handicapped and those who are not.

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*Lou Brown, Betsy Shiraga, Patty Rogan, Jennifer York, Kathy Zanella, Eileen McCarthy, Ruth Loomis, and Pat VanDeventer. University of Wisconsin and Madison Metropolitan School District, 1985.

When services are provided is another factor to be examined. The normal rhythm of daily activities or the time schedules observed by people without handicaps should be the standard when arranging the activities of a person with severe handicaps. If a person is working at times other than a regular daytime shift or five mid-week days, then the schedule in the person's home shifts accordingly. When a person who is developmentally disabled has to work evenings or weekends, corresponding accommodations should be made in the arrangement.

If an adult with severe handicaps attends a developmental achievement center, supported employment opportunities in community businesses should be made available. But such employment cannot be maintained if there is no flexibility to accommodate evening, weekend and holiday work, which is often the type of entry-level jobs available for persons with severe handicaps.

What (materials, settings and equipment) is used in teaching skills and behaviors is also important. Are the setting, materials and equipment used typical for nonhandicapped persons of the same chronological age?

This is an especially important factor for adults. Teaching texture, discrimination and acquisition of fine motor skills to adults by using different colored pieces of wood shaped as squares, triangles and circles has little to do with skills a person needs for essential living tasks. Using a fork, a plate and a cup to set a table provides similar discrimination practice and fine motor exercises but it is directly related to a needed adult skill. Teaching this at break time or at lunch time in a day program or at breakfast or dinner time in the person's home is also consistent with use of normal time schedules and natural setting where the skills will be needed.

Reinforcers used to reward or motivate persons should also be similar to those used by or for persons without handicaps but in the same age group. Using "M and M's" or cookies are not what you would expect as a reward from one adult to another adult to let the person know the action was very nice or the correct thing to do. Creativity can identify other immediate reinforcers such as giving a flower, taking a Polaroid snapshot of the person, giving a pleasing picture for the person's room, etc.

Delayed reinforcers may include a visit with one's advocate, friends or family to an art or craft exhibit, or planting a flower in the person's home garden or in a flower pot that the individual could keep in his/her room at home. Somewhere in the past the adult was taught the candy/cookie reinforcement behavior. Accepting age-appropriate reinforcers can also be taught.

Dr. Brown's list also mentions other related factors that should be considered:

- Is the learning time needed to acquire skills and behavior reasonable?
- Will many opportunities to practice the skills and behaviors be available?
- Will acquisition of these new skills and behaviors open new opportunities for the person to enjoy a wider range of experiences?

Appendix G

Minnesota Case Management Appeal Procedures

The *conciliation conference* is an informal way for the individual and family to express dissatisfaction about their case management services or the inadequacy of other services. A letter stating the problem and requesting a conciliation conference should be sent to the county. Usually the individual, the case manager, the county supervisor and a representative of the Minnesota Department of Human Services attend the conference.

Whoever requests the conference should provide information on what the problem is, examples of the problem, and what the county is expected to do to correct it. A written list is helpful. At the conference, the county and those who requested the meeting will discuss the problem and probably reach a decision then or later. The county must communicate its decision within 30 days of the date of the conciliation conference.

If there is still dissatisfaction, or if the county has not responded in 30 days, then a *social service appeal* may be filed within 90 days of the conciliation conference.

The social service appeal is a more formal process. It usually covers problems such as a suspension, reduction, denial or termination of services, or failure of the county to act within specified timelines. A written request for this appeal should be sent to the county. The appeal is heard by a referee who issues a recommendation which is sent to the commissioner of the Minnesota Department of Human Services. The appeal recommendation has to be issued as a final order by the commissioner within 60 days of the request for an appeal. If the commissioner does not accept the referee's recommended order, a final order must be issued within 90 days of the requested appeal.

Appendix H

Guardianship in Minnesota

The purpose of a guardianship is to insure that appropriate decisions are made for persons who are unable to make decisions for themselves. This is true for both minors and adult persons who are deemed incompetent. The critical factor is that the person must be unable to make responsible decisions for him or herself.

In Minnesota there are three types of guardianship:

- Commissioner's (state) guardianship for dependent and neglected children. This involves a state agency acting as guardian for children whose parental rights have been terminated. The commissioner delegates supervision and the majority of consents to local social service agencies. This guardianship ends at age 18. Commissioner's guardianship for dependent and neglected children is governed by Minnesota Statutes, sec. 260.242, as an effect of Minnesota Statutes, sec. 260.241.
- Commissioner's (state) guardianship/conservatorship for mentally retarded adults. This involves a state agency acting as guardian for mentally retarded adults who typically do not have family or friends to act on their behalf. The majority of powers of the guardian have been delegated to the local county social worker. Commissioner's guardianship for mentally retarded adults is governed by Minnesota Statutes, sec. 252, the Mental Retardation Protection Act.
- Private guardianship/conservatorship. This involves a private party, such as a relative or close friend, assuming the role of guardian. Private guardianship is generally considered less restrictive than public guardianship. This type of guardianship is governed by Minnesota Statutes, sec. 525.539 to 525.61.

The private guardianship law allows the county to act as guardian for those vulnerable adults in danger of serious abuse or neglect. This has been typically used for older persons. Also a few corporations in Minnesota provide guardianship services for various populations.

A guardian may be an individual, organization, or state agency appointed by a court and given the authority to make decisions on behalf of a person determined by a court to be legally incompetent. A ward is a person for whom a guardian has been appointed.

Conservatorship in Minnesota is a limited form of guardianship. In other states it may only refer to a guardian of the estate. Conservatorship in Minnesota restricts only those portions of the rights as stated in the court-ordered warrant of conservatorship commitment. It does not take away a person's fundamental civil right to vote and does not deem the person a legally incompetent person. A conservatee is a person for whom a conservator has been appointed.

Guardianship/conservatorship results in either total or partial loss of rights and decision-making power for the person. This means that the individual's needs must be paramount in the decision to seek guardianship.

Guardianship/conservatorship, when used improperly, may result in a total denial of the rights of the person. For a person with slightly impaired decision-making skills, the loss of all of those rights might be unthinkable unless there is a demonstrated need for protection which is substantially more important for the welfare of the person than the loss of such rights.

In contrast, the loss of such rights for individuals with significantly impaired decision-making skills may involve no real loss since they would not actually be exercising these rights. Their need for protection may be much more important for their welfare than retention of legal capacity. A properly affirmative guardianship provides a means by which rights may be asserted.

Guardianship is not necessarily the only solution to problems. Before seeking guardianship/conservatorship, there should be a compelling reason which is in the best interest and welfare of the person, and the advantages should clearly outweigh the disadvantages.

(The above information was provided by Kay C. Hendrikson; Public Guardianship Administrator; Quality Assurance and Protective Services; Fourth Floor, Centennial Office Building; St. Paul, MN 55155.)

Appendix I

Preference/Choice-Making Bibliography*

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*Compiled by Ginny Gadbois Green for the MNASH Adult Service Committee

Appendix J

An Associational Map*

ARTISTIC ORGANIZATIONS:	choral, theatrical, writing
BUSINESS ORGANIZATIONS:	chambers of commerce, neighborhood business associations, trade groups
CHARITABLE GROUPS AND DRIVES:	Red Cross, Cancer Society, United Way
CHURCH GROUPS:	service, prayer, maintenance, stewardship, acolytes, men's, women's, youth, seniors
CIVIC EVENTS:	July 4th, art fair, Halloween
COLLECTORS GROUPS:	stamp collectors, flower dryers, antiques
COMMUNITY SUPPORT GROUPS:	"friends" of the library, nursing home, hospital
ELDERLY GROUPS:	senior citizens
ETHNIC ASSOCIATIONS:	Sons of Norway, Black Heritage Club, Hibernians
HEALTH AND FITNESS GROUPS:	bicycling, jogging, exercise
INTEREST CLUBS:	poodle owners, old car owners
LOCAL GOVERNMENT:	town, township, electoral units, fire department, emergency units
LOCAL MEDIA:	radio, newspaper, local access cable TV
INTEREST GROUPS:	cultural, political, social, educational, vocational
MUTUAL SUPPORT (SELF-HELP) GROUPS:	Alcoholics Anonymous, Epilepsy self-help, La Leche League
NEIGHBORHOOD AND BLOCK CLUBS:	crime watch, beautification, Christmas decorations
OUTDOOR GROUPS:	garden clubs, Audubon Society, conservation clubs
POLITICAL ORGANIZATIONS:	Democrats, Republicans, caucuses
SCHOOL GROUPS:	printing club, PTA, child care
SERVICE CLUBS:	Zonta, Kiwanis, Rotary, American Association of University Women
SOCIAL CAUSE GROUPS:	peace, rights, advocacy, service
SPORTS LEAGUES:	bowling, swimming, baseball, fishing, volleyball
STUDY GROUPS:	literary clubs, bible study groups
VETERANS GROUPS:	American Legion, Amvets, Veterans of Foreign Wars, their Auxiliaries
YOUTH GROUPS:	4H, Future Farmers, Scouts, YW/MCA

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*Compiled by John L. McKnight, Northwestern University, Center for Urban Affairs and Policy Research, 2040 Sheridan Rd., Evanston, IL 60201

Appendix K

TEST YOUR IQ Integration Quotient for Organizations Serving People with Developmental Disabilities*

ADMINISTRATION YES NO

1. Does your organization have a written policy, position or mission statement affirming the value of community integration for the individuals it serves? _____ _____

2. Has your organization provided in-service training on integration values, principles, and practices in the past year to:

   a. Administrative staff? _____ _____
   b. Supervisory and direct-care staff? _____ _____
   c. Board of directors? _____ _____
   d. Clients' families? _____ _____
   e. Organization volunteers? _____ _____

3. Does your organization provide up-to-date information on integration resources such as notices of relevant conferences, workshops, presentations by leading-edge professionals or recent books, journal articles, studies, and reports which feature integration concepts, principles and practices, and other state-of-the-art materials? _____ _____

4. Does your organization provide space on the premises (e.g., a library, resource room, bulletin board, or shelves) to display or circulate notices, articles, or books on integration? _____ _____

5. Does your organization provide tangible incentives (time off, registration fees, promotions, wage increases) to encourage professional development to keep current with new ideas in the field? _____ _____

CLIENTS

6. Does each of the clients you serve have an Individual Plan (Program, Habilitation, Education or Written Rehabilitation) that addresses basic human needs?

   a. To improve *personal status*, the plan should include activities designed to enhance self-image, abundant opportunities to make choices, and skills to reduce dependence on others for self-care. _____ _____

   b. To increase *community stature*, the plan should include activities that are generally valued by members of society who are not disabled. Typical community activities include getting a library card and using it, shopping as individuals rather than in groups, going to regular education classes with other children or adults who are not disabled. _____ _____

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*Developed for the Minnesota Governor's Planning Council on Developmental Disabilities, St. Paul, MN.

	YES	NO
7. Do each of your clients have at least four socially valued roles such as:		
a. *Homeowner, tenant,* or *roommate* (not facility resident)?	____	____
b. *Community volunteer* or member of a local club or group for people who are not disabled?	____	____
c. Recreational or leisure role, e.g., a *participant* or *spectator* in community sports, a *library card owner*?	____	____
d. A *student* in the local school or in regular adult education or vocational training classes, an *employee* in a business with a majority of coworkers who are not disabled, a *friend* or *companion* of at least two people who are not disabled other than family and staff?	____	____

ENVIRONMENT

8. Do the environments in which your clients spend most of their time reflect:		
a. *Attitudes* that affirm they have potential to grow that has yet to be developed regardless of their past performance?	____	____
b. *Expectations* that are high, demand higher achievements than past experience would predict, and recognize that the limitations of their environments have held them back more than their disabilities?	____	____
c. *Age-appropriate* settings, training materials, and equipment?	____	____
d. *Community-referenced* skills and behavior training?	____	____
e. *Functional* tasks and activities that are expected and valued by the community for persons their age?	____	____
f. *Individualized* approaches that are in a natural proportion (ratio of persons with disabilities to those who are not disabled) in living, learning, working, and social arrangements?	____	____

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